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ORIGINAL PAPER

Phenotypic Characteristics of Autism Spectrum Disorder in a Diverse Sample of Somali and Other Children

Amy N. Esler[1] · Jennifer Hall-Lande[2] · Amy Hewitt[2]

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Abstract The potential for culture to impact diagnosis of autism spectrum disorder (ASD) is high, yet remains largely unstudied. This study examined differences across racial/ethnic groups in ASD symptoms, cognitive and adaptive skills, and related behaviors in children with ASD that included a unique subgroup, children from the Somali diaspora. Somali children were more likely to have ASD with intellectual disability than children from all other racial/ethnic groups. Few differences were found in the presence of specific symptoms and behaviors across groups once IQ was controlled. Results lend support to previous studies that found higher rates of ASD intellectual disability in children of immigrants from low human resource index countries compared to other groups. Implications for future research are discussed.

Keywords Autism spectrum disorder · Intellectual disability · Phenotype · Racial-ethnic

Introduction

As awareness of autism has increased, the needs of diverse families with autism spectrum disorder (ASD) has received greater focus. Over the past decade, there has been a general trend of increasing prevalence of ASD in the United States, but rates of ASD among non-white children has remained lower than that of white children (Centers for Disease Control and Prevention [CDC] 2014, 2016a). At the same time, immigration patterns have led to increasing diversity within the U.S. In 2015, 13.2% of the total U.S. population was foreign-born, and between 2000 and 2015, the number of foreign-born increased by 10.6 million, representing close to a 20% increase (U.S. Census 2000, 2015). Immigrant groups themselves are increasingly diverse, with 46% of immigrants reporting Hispanic origins, 26% Asian, 9% black, and 15% other in 2015 (U.S. Census 2015). Refugees to the U.S. represent a subset of immigrants likely to have experienced high levels of adversity due to ethnic conflict or civil war. From 2006 to 2016, the U.S. has admitted between 40,000 and 85,000 refugees per year (U.S. Department of State 2017), and in fiscal year 2016, just over 37% of refugees were from Africa (U.S. Department of State 2016). The needs of immigrant and refugee families of children with ASD is an emerging area of research, and information is needed to inform clinical practice and policy in developing systems that are responsive and effective within diverse populations.

ASD is a complex condition with significant heterogeneity in characteristics across individuals. Although social communication deficits and restricted, repetitive behaviors are its hallmarks, ASD affects all aspects of development and often co-occurs with intellectual disability, speech-language impairment, and behavioral and psychological conditions (e.g., aggression, attention deficit hyperactivity disorder, anxiety). Due to the reliance on behavioral characteristics of ASD—in particular, behaviors of social interaction and communication—the potential for culture to impact ASD diagnosis cannot be underestimated. Yet to

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✉ Amy N. Esler
esle0007@umn.edu

[1] Department of Pediatrics, University of Minnesota, 717 Delaware St SE, Minneapolis, MN 55414, USA

[2] Institute on Community Integration, University of Minnesota, 150 Pillsbury Dr SE, Minneapolis, MN 55455, USA

date, little research has explored differences in behavioral characteristics of ASD across cultures. The most consistent finding in the U.S. is that prevalence rates differ by race/ethnicity, with white children having a significantly higher prevalence than Hispanic, black, and Asian children (CDC 2014, 2016a; Mandell et al. 2009; Morrier et al. 2008). Differences across race may be connected to socioeconomic status. A positive relationship has been found between socioeconomic status and ASD prevalence across racial/ethnic groups (Durkin et al. 2010). In the U.S., lower ASD prevalence among black and Hispanic children was only seen in the low SES category, suggesting that higher rates of poverty within these groups may contribute to their lower overall ASD prevalence. Other researchers also have argued that wealthier, more educated families are more likely to access specialized services for ASD that allow them to obtain a diagnosis (Fombonne 2003; Liptak et al. 2008; Mandell et al. 2005; Newschaffer et al. 2007).

The opposite trend has been observed in studies of ASD prevalence among recent immigrants from low human development index countries (Barnevik-Olsson et al. 2008; Gillberg 1987; Hassan 2012; Keen et al. 2010). A British research study reported ASD prevalence in Somali, Black African, and Black Caribbean children at least twice that of all other ethnic groups in the study (Hassan 2012). Keen et al. (2010) also found a higher risk for ASD in children of immigrant mothers from Caribbean and African countries. In a 2008 report, a group of Swedish researchers found a higher prevalence of ASD among Somali children compared to non-Somali children (Barnevik-Olsson et al. 2008).

Studies of ASD in recent immigrant families also have found an unusually high rate of co-occurring intellectual disability (ID). In the 2008 report on Somali children in Sweden, all of the Somali children in the sample (n = 17) had a co-occurring diagnosis of ID (Barnevik-Olsson et al. 2008), a rate four to five times higher than that of non-Somali children (Barnevik-Olsson et al. 2010). Further, 80% of Somali children with ASD had "exceptionally marked" hyperactivity (Barnevik-Olsson et al. 2010, p. 1168). A similar study in Ireland found that a higher proportion (72.2%) of children of African immigrants had ASD with moderate or severe ID compared to other groups (Bolton et al. 2014). Magnusson et al. (2012) linked increased prevalence of ASD with ID, but not ASD without ID, with migration occurring within 1 year pre- or postnatally, and risk for ASD with ID was highest when families migrated from regions with a low human development index. Most recently, a cohort study in Western Australia found that immigrant families from East Africa had over 3.5 times the odds of ASD with intellectual disability compared to white, native-born (Fairthorne et al. 2017). It should be noted that these studies involved very small numbers of immigrant families, and authors emphasized the need for replication. However, the above results raise questions about whether immigrant groups from low human resource index countries experience greater functional impairment with ASD than other groups. If this is the case, there could be implications for causal mechanisms (e.g., differences in genetic risk and/or stressors to the prenatal environment) as well as for understanding sociocultural dynamics, such as health disparities (e.g., bias in diagnostic practices, barriers to obtaining diagnosis except in the most impaired cases, differential access to effective treatments) and cultural differences in help-seeking (e.g., lack of culturally sensitive diagnostic and intervention procedures, stigma, differences in beliefs about child development).

The present work presents a subset of findings from the Minneapolis Somali Autism Spectrum Disorder Prevalence Project (MSASDPP), a study of ASD prevalence in Minneapolis with a focus on prevalence among children from the Somali diaspora (Hewitt et al. 2016). Minnesota has the highest number of Somali refugees and immigrants in the U.S., with estimates of 46,300 people of Somali ancestry living in the state (Minnesota State Demographic Center 2016). Minneapolis was the site of this investigation due to its large population of roughly 15,000 Somalis (Census Bureau 2015). The project examined medical and educational records of Minneapolis children who were ages 7–9 in 2010 using a modified version of Autism and Developmental Disability Monitoring (ADDM) Network methods (Rice et al. 2007). Overall findings from that study indicated that ASD prevalence did not differ statistically between white and Somali children, with rates of 1 in 36 and 1 in 32, respectively. White and Somali children had significantly higher prevalence rates than Hispanic (1 in 80) and non-Somali black children (1 in 62). Asian and Native American children were included in the project but had such low numbers of children meeting criteria for ASD that they were not able to be included in prevalence calculations.

MSASDPP identified cases of ASD through multi-step review of educational and medical records, and data were collected on the presence of core symptoms of ASD and additional medical, behavioral, and developmental features often related to ASD. The current study examines differences in ASD symptomatology and associated features across racial/ethnic groups. The study contributes to past research on racial/ethnic differences in ASD by including a population sample with a unique subgroup, Somali children, for whom there is some evidence of higher rates of ASD with an atypically severe presentation. The presence and severity of ID were examined as well as presence of DSM-IV-TR (American Psychiatric Association [APA] 2000) symptoms across racial/ethnic groups. Metrics of ASD symptom severity were estimated to examine whether

the reported severity of ASD among Somali children went beyond level of cognitive functioning. These findings add to the emerging literature on ASD in African immigrant/refugee families to further establish trends in how ASD manifests within children from these populations. Based on this work, we suggest avenues for future research regarding potential causal mechanisms and/or health disparities; the methodology employed is not intended or able to address questions of causality or biological risk.

Methods

The project implemented a single-site, multiple-source, records-based public health surveillance methodology modified from the CDC's ADDM methodology (Rice et al. 2007). To ensure adequate sample size for prevalence estimates, children who were age 7–9 years and who had one parent or legal guardian living in the city of Minneapolis in the calendar year 2010 were included. The project received Internal Review Board (IRB) approval from the University of Minnesota and Minneapolis Public Schools (MPS). In MPS, a passive consent process was implemented to provide the opportunity for parents to decline participation in surveillance. The consent protocol was translated into languages that MPS commonly translated and sent to all families who had a child attending MPS who had ever received special education services and who was 7–9 years of age in 2010. Clinic source records were accessed through an agreement with the Minnesota Department of Health.

Study Area and Population Characteristics

During the 2010 surveillance year, the Minneapolis population of children age 7–9 represented 5.8% (=12,339/211,257) of all Minnesota children age 7–9. Approximately 35% of Minneapolis 7–9-year-olds was white, 35% was black, 19% was Hispanic, 7% was Asian, and 3% was Native American. Somali children represented slightly less than 25% of all black children and 8.2% of the overall population of Minneapolis 7–9-year-olds.

Identification of Somali Children

Identifying children from the Somali diaspora presented a unique challenge, and multiple methods were considered. Given the known constraints of the information contained in educational and medical records, three possible methods of defining Somali status were identified: (1) primary language spoken in the home is Somali, (2) the record contains any reference to being of Somali descent (e.g., mentions Somali heritage, indicates a Somali interpreter was present), or (3) Somalia is listed as the mother's country of origin on the child's birth certificate. Each method had known limitations. Information on primary language spoken in the home is routinely collected in public schools at the time of a student's enrollment but may not be systematically collected in health/clinic records. Further, birth certificate data were not available for children born outside the state of Minnesota. The three possible definitions of Somali status were compared and yielded similar results. Using Somali as the primary language in the home, 31 children with ASD case status were identified as Somali. Using any reference to Somali in a record, 34 children with ASD were identified as Somali. Using birth certificate data, 27 children with ASD were identified as Somali; 4 of the 31 children identified based on primary language and 6 of the 34 children identified based on any reference to Somali were born outside of Minnesota. In consultation with epidemiologists from the Minnesota Department of Health and the CDC and with our community advisory group that included stakeholders from the Somali community, it was ultimately determined that primary language spoken in the home would be the most reliable, replicable indicator of Somali status.

Case Identification

Case identification of ASD involved two phases. Phase 1, screening and abstraction, included the review of educational records for all children born in 2001, 2002, and 2003 who had ever received special education services and the review of clinic source health records in primary clinics where assessment, diagnosis, and treatment of various developmental disabilities (including ASD) occur. Further information on the selection of schools and clinics is available in Hewitt et al., 2014. Trained abstractors reviewed these records to identify behavioral descriptions that met specific inclusion criteria. Specifically, records were reviewed for behavioral descriptions that reflected DSM-IV-TR (APA 2000) symptoms of autistic disorder—these are referred to as "social behavioral triggers." For example, poor eye contact, no response to name, or lack of interest in peer interaction would be considered triggers. Records also were reviewed for "associated features," which refer to behaviors and characteristics that often co-occur with a diagnosis of ASD but are not tied to a DSM-IV-TR category. For example, unusual responses to certain types of sensory stimuli are a commonly noted feature of ASD but were not explicitly part of the diagnostic criteria under the DSM-IV-TR; they were coded as an associated feature. Associated features also included behavioral and medical/developmental concerns commonly associated with ASD, such as aggression, hyperactivity/inattention, motor deficits, sleeping or eating problems, and seizures. Regular internal quality control checks were performed to

ensure reliability was maintained among the field abstractors, including routine monitoring for accuracy by the project coordinator and on-site review by the CDC to check quality and accuracy of the review and abstraction of data completed by each of the abstractors. In phase 2, clinician review, clinicians reviewed the abstracted data to determine ASD case status using a coding scheme based on DSM-IV-TR criteria. If a child displayed behaviors from birth through age 9 on a comprehensive evaluation by a qualified professional that were consistent with the DSM-IV-TR diagnostic criteria for autistic disorder, pervasive developmental disorder—not otherwise specified (PDD-NOS, including atypical autism), or Asperger disorder, the child met ASD surveillance case definition. This method allows for identification of ASD cases even when a formal diagnosis of ASD has not been made. Clinician reviewers had expertise in diagnosis of ASD and completed training and ongoing reliability checks on a blinded, random sample of ≥10% of records. Inter-rater agreement on case status (confirmed ASD vs. not ASD) was established at 90% and subsequently maintained at 89% (k = 0.77) throughout the duration of the study.

The total number of educational records reviewed from all schools included in the study was 1241, and 487 of these files met criteria for a full abstraction. There were 502 missing files in schools, which includes 307 excluded due to the passive consent requirement. Of the 307, only five consent forms were returned indicating the family wished to be excluded. The remaining 302 were returned undeliverable by the post office. The total number of records reviewed through clinic sources was 3312, with 264 receiving a full abstraction and five missing records. Information on credentials of the evaluators and the use of ASD-specific measures is provided in Supplemental Tables 1 and 2. For ASD cases, 70.6% of records contained an ASD-specific measure, most of which were an ASD checklist. Less than half of these records (41.6%) included a direct measure of ASD symptoms, which was the Autism Diagnostic Observation Schedule (ADOS), and schools included an ADOS more frequently than non-school evaluators (46.4 vs. 14.8%).

Phenotypic Data

In addition to coding DSM-IV-TR diagnostic criteria for ASD case status, clinician reviewers systematically recorded additional information for each case, including: (a) concerns regarding the child's development by age 3 years focused on social, language, and imaginative play skills, as well as any mention of regression or plateau in skill development; (b) functional skills, including scores on tests of intellectual ability and adaptive skills; (c) autism discriminators, which referred to descriptions of behaviors that are hypothesized to distinguish children with ASD from children with other developmental disabilities; and (c) associated features. Children were classified as having co-occurring ID if they had an intelligence quotient (IQ) score of ≤70 on their most recent test available in the record. In the absence of a specific IQ score, an examiner's statement about the child's intellectual ability, if available, was used to classify the child's ID status. Autism discriminators included behaviors reflecting lack of awareness of others, lack of interest in social interaction, rare or absent social initiations or responses, and the presence of marked restricted, repetitive behaviors. Discriminators were identified through a review of the literature and through the Metropolitan Atlanta ADDM clinician team as behaviors strongly indicative of ASD, such as being oblivious to others when there is a clear social opportunity or demonstrating atypical and persistent focus on sensory input (Rice et al. 2007).

Severity of ASD Symptoms

Severity of autism symptoms was estimated in three ways: (1) reviewer certainty ratings were compared across groups, as higher certainty could indicate the presence of more significant symptoms; (2) the number of DSM-IV-TR symptoms present in the records was summed and compared across groups; and (3) the number of recorded autism discriminators was compared across groups. Discriminators are assigned when the behavior characterizes the child over time and across situations and is of significant intensity or frequency to reasonably cause functional or other limitations (CDC 2016b), making them potential markers of symptom severity.

Statistical Analyses

Frequencies and percentages were used to describe DSM-IV-TR symptoms and associated features and were compared across Somali, white, non-Somali black, and Hispanic children with a case status of ASD. Categorical differences in ASD symptoms, ID status, and associated features across racial/ethnic groups were assessed with Chi square analyses for nominal data (χ^2), and odds ratios (OR) with confidence intervals (CI) of 95% were used to estimate effect size. Differences in number of symptoms and features documented across racial/ethnic groups were compared using ANOVA. All analyses were run for the total sample, and, when power was adequate, for the sample of children with ASD with ID. Hispanic children were excluded from analyses with ASD with ID due to low sample size. Power analyses were run for analyses of symptom profiles and severity to establish the minimum detectable difference allowed based on the available sample size,

assuming 80% power at a Type II error rate of 5%. For all severity comparisons, sample size for the total sample was adequate to detect mean differences of one or more DSM-IV-TR criteria and autism discriminators for the total number of symptoms as well as by domain. For the ASD with ID sample, this varied by metric, and comparisons were calculated where applicable. Data analyses were performed using SPSS version 22.0.

Results

Characteristics of Surveillance Cases

Two-hundred and thirty-four children met ASD case definition. Of these, 120 (51.2%) were white, 53 (22.6%) were non-Somali black, 31 (13.2%) were Somali, and 30 (12.8%) were Hispanic. The sample was comprised of 82.1% males and 17.9% females, yielding a male to female ratio of 4.6:1.0. The male to female ratio varied across racial/ethnic groups; sample size was not large enough to detect statistically significant differences in sex ratios across groups.

Co-occurring Intellectual Disability Across Racial/Ethnic Groups

Overall, 72.6% of children who met ASD surveillance case definition had cognitive data available in their records. Differences across racial/ethnic group in the percentages of children with cognitive data were not statistically significant: 74.2% of white, 81.1% of non-Somali black, 60.0% of Hispanic and 64.5% of Somali children's records contained cognitive data.

Among the children with confirmed ASD for whom there was cognitive data, 33% had intellectual disability (ID), representing approximately 31% of girls (=10/32) and 33% of boys (=45/138) with confirmed ASD. The proportion of Somali children with ID was higher and statistically significant when compared to white ($\chi^2 = 45.77$, $p < .001$, OR 4.94, CI 3.27–7.47), non-Somali black ($\chi^2 = 26.64$, $p < .001$, OR 3.31, CI 2.10–5.21), and Hispanic children ($\chi^2 = 24.63$, $p < .001$, OR 4.50, CI 1.90–10.68). Because of small sample size, stratified analyses of the distribution of children by sex and race/ethnicity were not performed.

A distribution of cognitive levels by race/ethnicity among the 170 children with cognitive data in their records is shown in Table 1. Overall, 50% of children had average (IQ 86–115) or above average cognitive skills (IQ > 115) documented in records. Consistent with the overall pattern, roughly 50% of children who were white, non-Somali black, and Hispanic had average or above average cognitive skills. By contrast, all Somali children with ASD who had cognitive data in their records had mild, moderate, or severe cognitive impairments, with estimated IQs ranging from 20 to 70. Sample size would not permit comparisons of proportions of mild, moderate, and severe ID across racial/ethnic groups. However, Somali children appeared discrepant from other groups in the number of children classified with cognitive impairment, not otherwise specified (NOS), which captures cases where ID is present, but the examiners did not indicate a score or report a level of severity. Power was adequate to compare this classification

Table 1 Cognitive levels for confirmed ASD cases with cognitive data in their records

	Total ($n = 170$)	Hispanic ($n = 18$)	White ($n = 89$)	Black, non-Somali ($n = 43$)	Somali ($n = 20$)
Cognitive levels	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Above average IQ > 115	9 (5.3)	0	8 (9.0)	1 (2.3)	0
Average IQ 86–115	79 (46.5)	11 (61.1)	47 (52.8)	21 (48.4)	0
Borderline IQ 71–85	27 (15.9)	3 (16.7)	16 (18.0)	8 (18.6)	0
All intellectual disability	55 (23.5)	4 (22.2)	18 (20.2)	13 (30.2)	20 (100)[a,b,c]
Mild impairment IQ 50–70	12 (7.0)	2 (11.1)	2 (2.3)	5 (11.6)	3 (15.0)
Moderate impairment IQ 35–49	8 (4.7)	1 (5.6)	4 (4.5)	1 (2.3)	2 (10.0)
Severe impairment IQ 20–34	5 (2.9)	0	1 (1.1)	0	4 (20.0)
Profound impairment IQ < 20	0	0	0	0	0
Cognitive impairment NOS*	30 (17.6)	1 (5.6)	11 (12.4)	7 (16.3)	11 (55.0)[b]

*Cognitive impairment not otherwise specified (NOS) refers to cases where the examiner made a statement indicating the presence of intellectual disability or significant cognitive impairments but did not report standardized test scores

[a] Somali > Hispanic, $p < .001$

[b] Somali > white, $p < .001$

[c] Somali > non-Somali black, $p < .001$

for Somali and white children, and the difference was significant ($\chi^2 = 47.09$, $p < .001$, OR 8.67, CI 2.93–25.62).

Adaptive skills were less reliably reported in records than cognitive data. Of 234, 137 (58.5%) children with ASD had some kind of adaptive skill assessment documented, and of these, 96 included either a standard score or qualitative information on adaptive skill level. Children with ASD with ID were most likely to have adaptive skill testing documented in their records; of 55 children with ID, 46 (83.6%) had adaptive skill testing. Of the full sample of children with ASD with adaptive tests in their records, 45.9% had adaptive skills of 70 or lower and 45.7% of children with ASD with ID had adaptive skills in this range. Sample size did not allow for comparisons across race/ethnicity.

Patterns of ASD Symptoms Present

Looking at patterns of individual DSM-IV-TR symptoms (Table 2), within the total sample, Somali children were coded as displaying the Social Interaction criterion (1c) of lack of spontaneous seeking to share enjoyment, interests, or achievements with others more often than white ($\chi^2 = 5.31$, $p = .021$, OR 4.00, CI 1.42–14.00) and Hispanic ($\chi^2 = 7.56$, $p = .006$, OR 6.22, CI 1.54–25.15) children. The Communication criterion (2d) of lack of varied, spontaneous make-believe play or social imitative play was noted more often for Somali children compared to white ($\chi^2 = 8.04$, $p = .005$, OR 6.72, CI 1.52–29.63), non-Somali black ($\chi^2 = 6.55$, $p = .011$, OR 6.27, CI 1.33–29.49), and Hispanic ($\chi^2 = 6.97$, $p = .008$, OR 7.25, CI 1.43–36.69) children. Regarding Restricted/Repetitive Behaviors, encompassing preoccupation with one or more stereotyped and restricted patterns of interest (criterion 3a) was noted more frequently for white children than Hispanic children ($\chi^2 = 7.03$, $p = .008$, OR 3.06, CI 1.31–7.15). White ($\chi^2 = 6.43$, $p = .011$, OR 2.97, CI 1.25–7.05) and Somali ($\chi^2 = 7.56$, $p = .006$, OR 6.22, CI 1.54–25.15) children were documented more often than Hispanic children with stereotyped and repetitive motor mannerisms (criterion 3c). Finally, preoccupation with parts of objects (criterion 3d) was noted more frequently for Somali children than Hispanic children ($\chi^2 = 7.02$, $p = .008$, OR 5.16, CI 1.44–18.46). Results are summarized in Table 2.

Differences were found within the total sample in autism discriminators of lack of pretend play and lack of response to the social approach of others. Somali children were coded more frequently has having a lack of response to the social approach of others than white children ($\chi^2 = 20.02$, $p < .001$), and Somali children were coded more frequently with lack of pretend play than white ($\chi^2 = 21.96$, $p < .001$, OR 6.88, 95% CI 2.89–16.37) and non-Somali black children ($\chi^2 = 8.97$, $p < .01$, OR 4.15, 95% CI 1.60–10.79) (Table 3).

Sample sizes were not adequate to compare groups of children with ASD with ID on frequencies of DSM-IV-TR symptoms or autism discriminators. However, in the case of DSM-IV-TR symptoms, all racial/ethnic groups had high rates of symptom endorsement (Table 2). Regarding discriminators, two of the largest differences across groups (i.e., >20% points) were in areas that were identified as statistically significant for the total sample: lack of pretend play and lack of response to the social approach of others, and Somali children had higher frequencies of endorsement than white and black children (Table 3).

ASD Symptom Severity

Reviewer Certainty Ratings

Certainty ratings were assigned during clinician review on a scale from 1 to 5, with 5 indicating the highest level of certainty. No statistically significant differences were detected in mean clinician reviewer certainty ratings across racial/ethnic groups for the full sample $F(3, 230) = 2.12$, $p = .099$. All groups had mean certainty ratings greater than 4. Tukey HSD post-hoc test results indicated a non-significant trend of higher certainty ratings for Somali children compared to Hispanic children ($p = .086$). When the sample was restricted to ASD with ID, power was adequate to detect mean differences of 0.5 or higher. No statistically significant differences were detected, Welch $F(2, 28.75) = 1.56$, $p = .228$; all groups had mean certainty ratings of 4.5 or higher.

Number of DSM-IV-TR Symptoms Documented in Records

Racial/ethnic groups were compared in number of DSM-IV-TR symptom criteria met overall and by domain (i.e., Social Interaction, Communication, and Restricted/Repetitive Behaviors). The assumption of homogeneity of variance was violated for Social Interaction and Restricted, Repetitive Behaviors domain subtotals; thus, the Welch F-ratio is reported for these variables. Where homogeneity of variance could not be assumed, Games-Howell post-hoc tests were used; otherwise, Tukey HSD was used. Effect of race/ethnicity on mean total number of DSM-IV-TR symptoms approached significance, $F(3, 230) = 2.59$, $p = .053$, $\eta^2 = 0.03$. In this case, the trend was for Hispanic children to have fewer overall symptoms of ASD documented in their records than Somali children ($p = .044$, $d = 0.71$). There were no differences in number of Social Interaction, $F(3, 78.62) = 1.56$, $p = .207$, or Communication, $F(3, 230) = 0.747$, $p = .525$, symptoms documented. There was a significant effect of race/ethnicity on mean number

Table 2 Number and percentage of children meeting individual DSM-IV-TR criteria by race/ethnicity and Somali status (all ASD cases)

	All ASD cases					ASD + ID (IQ ≤ 70)		
	Total ($N=234$)	Hispanic ($n=30$)	White ($n=120$)	Black, non-Somali ($n=53$)	Somali ($n=31$)	White ($n=18$)	Black, non-Somali ($n=13$)	Somali ($n=20$)
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Social Interaction								
Impairment in use of nonverbal behaviors	225 (88.2)	26 (86.7)	109 (90.8)	44 (83.0)	28 (90.3)	18 (100)	12 (92.3)	19 (95.0)
Peer relationships	238 (93.3)	30 (100)	110 (91.7)	48 (90.6)	30 (96.8)	17 (94.4)	13 (100)	20 (100)
Lack of sharing of enjoyment and interests	185 (72.5)	18 (60.0)	84 (70.0)	39 (73.6)	28 (90.3)[a,b]	16 (88.9)	13 (100)	19 (95.0)
Lack of social reciprocity	250 (98.0)	29 (96.7)	118 (98.3)	52 (98.1)	30 (96.8)	18 (100)	13 (100)	19 (95.0)
Communication								
Delay in spoken language	233 (91.4)	29 (96.7)	105 (87.5)	51 (96.2)	31 (100)	18 (100)	12 (92.3)	20 (100)
Impairment in conversation	236 (92.5)	29 (96.7)	110 (91.7)	50 (94.3)	27 (87.1)	17 (94.4)	13 (100)	18 (90.0)
Stereotyped and repetitive language	218 (85.5)	24 (80.0)	106 (88.3)	42 (79.2)	25 (80.6)	16 (88.9)	12 (92.3)	16 (80.0)
Lack of make-believe or social imitative play	184 (72.2)	20 (66.7)	82 (68.3)	37 (69.8)	29 (93.5)[c,d,e]	16 (88.9)	11 (84.6)	20 (100)
Restricted, repetitive behaviors								
Preoccupation	188 (73.7)	17 (56.7)	96 (80.0)[f]	36 (67.9)	21 (67.7)	16 (88.9)	11 (84.6)	14 (70.0)
Inflexible routines and rituals	237 (92.9)	26 (86.7)	114 (95.0)	50 (94.3)	29 (93.5)	16 (88.9)	13 (100)	19 (95.0)
Motor mannerisms	200 (78.4)	18 (60.0)	98 (81.7)[g]	41 (77.4)	28 (90.3)[h]	16 (88.9)	11 (84.6)	18 (90.0)

Table 2 (continued)

	All ASD cases					ASD + ID (IQ ≤ 70)		
	Total ($N=234$)	Hispanic ($n=30$)	White ($n=120$)	Black, non-Somali ($n=53$)	Somali ($n=31$)	White ($n=18$)	Black, non-Somali ($n=13$)	Somali ($n=20$)
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Preoccupation with parts of objects	190 (74.5)	17 (56.7)	94 (78.3)	36 (67.9)	27 (87.1)[i]	16 (88.9)	12 (92.3)	18 (90.0)

[a]Somali > Hispanic, $\chi^2=7.56$, p = .006, OR 6.22, CI 1.54–25.15

[b]Somali > White, $\chi^2=5.31$, p = .021, OR 4.00, CI 1.42–14.00

[c]Somali > Hispanic, $\chi^2=6.97$, p = .008, OR 7.25, CI 1.43–36.69

[d]Somali > White, $\chi^2=8.04$, p = .005, OR 6.72, CI 1.52–29.63

[e]Somali > non-Somali black, $\chi^2=6.55$, $p=.011$, OR 6.27, CI 1.33–29.49

[f]White > Hispanic, $\chi^2=7.03$, p = .008, OR 3.06, CI 1.31–7.15

[g]White > Hispanic, $\chi^2=6.43$, p = .011, OR 2.97, CI 1.25–7.05

[h]Somali > Hispanic, $\chi^2=7.56$, p = .006, OR 6.22, CI 1.54–25.15

[i]Somali > Hispanic, $\chi^2=7.02$, p = .008, OR 5.16, CI 1.44–18.46

of Restricted/Repetitive Behaviors, F (3, 75.55) = 4.13, p = .009, $\eta^2=0.004$. Hispanic children had fewer Restricted/Repetitive Behaviors coded in their records than white (p = .016, $d=0.22$) and Somali (p = .023, $d=0.43$) children, who did not differ from each other.

Selecting only children with ASD with ID, no differences between race/ethnicity and mean number of domain or total symptoms were detected either for the total number of DSM-IV-TR symptoms or for each domain. The sample was adequately powered to detect mean differences of 1.5 or more in total number of symptoms and of 0.5 or more within each domain. Table 4 shows mean totals of DSM-IV-TR symptoms by domain and overall, for the full sample and for children with ID.

Number of Autism Discriminators

Results of the one-way ANOVA were significant, F (3, 230) = 3.401, p = .019, $\eta^2=0.04$, and Tukey post-hoc tests revealed that Somali children had more autism discriminators coded in their records than white children (p = .012, $d=0.56$). There was a nonsignificant trend for Somali children to have more discriminators than Hispanic children (p = .055). Discriminators were next divided into behaviors reflecting social communication symptoms and behaviors reflecting restricted, repetitive behaviors. Differences in number of social communication symptoms were statistically significant (Welch F (3, 71.53) = 5.05, p = .003, $\eta^2=0.09$), with Somali children having more social communication discriminators than white children (p = .004, $d=0.83$). Table 4 presents these results.

When the sample was limited to Somali, non-Somali black, and white children with ASD with ID, no significant differences in total number of discriminators [F(3,51) = 0.948, p = .424], total social communication discriminators [F(3, 51) = 0.947, p = .425], or total repetitive behavior discriminators [F(3, 51) = 1.053, p = .377] were found (Table 4). Sample size was adequately powered to detect a difference of 2 or more in Total discriminators, a difference of 1.5 or more Social Communication discriminators, and a difference of 1.5 or more RRB discriminators.

Associated Features

For the full sample, there was no significant effect of race/ethnicity on number of associated features documented in records, F(3, 230) = 1.18, p = .318. The same was true for children with ASD with ID, F(3, 51) = 0.94, p = .429. For the full sample, over 80% of children with confirmed ASD were identified with the following associated features: abnormal mood/affect, argumentative/oppositional, hyperactivity/attention problems, and odd response to sensory stimuli. Other common associated features identified in at least 60% of children overall included abnormal eating/drinking, aggression, delayed motor functioning, and lack of or excessive fear. Somali children were significantly more likely to have atypical eating/drinking habits than white and non-Somali black children. Sample size was inadequate to examine differences in number of individual or total number of associated features for ASD with ID. Results are shown in Table 5.

Table 3 Frequency of autism discriminators coded in records by race/ethnicity

	All ASD cases					ASD + ID (IQ ≤ 70)*		
	Total $N = 234$	Hispanic $n = 30$	White $n = 120$	Non-Somali Black $n = 53$	Somali $n = 31$	White $n = 18$	Non-Somali Black $n = 13$	Somali $n = 20$
	N (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Oblivious to children	17 (7.3)	0 (0)	6 (5.0)	6 (11.3)	5 (16.1)	1 (5.6)	4 (30.7)	4 (20.0)
Oblivious to adults	19 (8.1)	3 (10)	8 (6.7)	4 (7.5)	4 (12.9)	2 (11.1)	0	2 (10.0)
Lack of response to approach of others	10 (4.3)	0 (0)	0 (0)	5 (9.4)	5 (16.1)[a]	0	2 (15.4)	5 (25.0)
Echolalia	8 (3.4)	2 (6.7)	1 (0.1)	1 (1.9)	4 (12.9)	0	1 (7.7)	3 (15.0)
Lack of showing	12 (5.1)	1 (3.3)	4 (3.0)	1 (1.9)	6 (19.3)	1 (5.6)	0	6 (30.0)
Little interest in others	86 (36.8)	11 (36.7)	38 (31.7)	21 (39.6)	16 (51.6)	9 (50.0)	7 (53.8)	12 (60.0)
Uses others as tools	12 (5.1)	4 (13.3)	3 (2.5)	2 (3.8)	3 (9.7)	2 (11.1)	2 (15.4)	3 (15.0)
Repeats dialogue	7 (3.0)	0 (0)	6 (5.0)	1 (1.9)	0 (0)	2 (11.1)	0	0
Lack of pretend play	54 (23.1)	7 (23.3)	18 (15.0)	12 (22.6)	17 (54.8)[b,c]	5 (27.8)	5 (38.5)	12 (60.0)
Restricted interests	10 (4.3)	0 (0)	7 (5.8)	1 (1.9)	2 (6.5)	3 (16.7)	0	1 (5.0)
Unusual preoccupation	51 (21.8)	5 (16.7)	31 (25.8)	9 (17.0)	6 (19.3)	5 (27.8)	4 (30.7)	3 (15.0)
Insistence on sameness	86 (36.8)	10 (33.3)	50 (41.7)	20 (37.7)	6 (19.3)	5 (27.8)	5 (38.5)	5 (25.0)
Nonfunctional routines	44 (18.8)	4 (13.3)	28 (23.3)	5 (9.4)	7 (22.6)	5 (27.8)	2 (15.4)	5 (25.0)
Focus on parts	5 (2.1)	0 (0)	3 (2.5)	1 (1.9)	1 (3.2)	0	1 (7.7)	1 (5.0)
Visual inspection	25 (10.7)	4 (13.3)	11 (9.2)	6 (11.3)	4 (12.9)	4 (22.2)	4 (30.7)	4 (20.0)
Movement preoccupation	12 (5.1)	1 (3.3)	6 (5.0)	5 (9.4)	0 (0)	0	3 (23.1)	0
Sensory preoccupation	90 (38.5)	9 (30.0)	42 (35.0)	25 (47.2)	14 (45.2)	6 (33.3)	7 (53.8)	9 (45.0)

*Sample size not adequate to detect differences

[a]Somali > White, $\chi^2 = 20.02$, $p < .001$

[b]Somali > White, $\chi^2 = 21.96$, $p < .001$, OR 6.88, 95% CI 2.89–16.37

[c]Somali > non-Somali black, $\chi^2 = 8.97$, $p < .01$, OR 4.15, 95% CI 1.60–10.79

Developmental Regression

Developmental regression and plateau were noted in a minority of ASD cases: 14.1% of children in this sample had a loss of skills noted in their records, and 2% had a plateau of skills noted. The sample size of children who experienced plateau was too low for further analysis. Regarding regression, there were no statistically significant differences across racial/ethnic groups in whether a loss of skills was documented in their records ($\chi^2 = 2.60$, p = .458).

Discussion

Findings were presented from a study of ASD in Minneapolis on differences in prevalence across racial and ethnic groups, with children from the Somali diaspora as a population of interest. The aim of the present analyses was to compare phenotypic characteristics of ASD across racial/ethnic groups, which included white, black (non-Somali), Hispanic, and Somali children.

Presence of ID Across Cultural Groups

This study found that 100% of Somali children with cognitive data in their records had IQ scores in the ID range (IQ ≤ 70) compared with 32.6% for the total sample. This was the most striking difference across racial and ethnic groups and was consistent with studies conducted in Sweden (Barnevik-Olsson et al. 2008) that also found that 100% of Somali children with ASD had co-occurring ID, as well as in Europe and Australia, where increased rates of ASD with ID for children of African immigrants were found (Bolton et al. 2014; Fairthorne et al. 2017; Hassan 2012; Magnusson et al. 2012).

This finding raises important questions about causal mechanisms and risk factors for Somali children with ASD.

Table 4 Number of DSM-IV-TR domain and total symptom criteria and autism discriminators met by race/ethnicity and Somali status (all ASD cases)

Number of criteria	All ASD cases					ASD + ID (IQ ≤ 70)		
	Total $N = 234$	Hispanic $n = 30$	White $n = 120$	Non-Somali Black $n = 53$	Somali $n = 31$	White $n = 18$	Non-Somali Black $n = 13$	Somali $n = 20$
DSM-IV-TR	M(SD)	M(SD)	M(SD)	M(SD)	M(SD)	M(SD)	M(SD)	M(SD)
Social interaction	3.52 (0.72)	3.43 (0.63)	3.51 (0.69)	3.45 (0.87)	3.74 (0.63)	3.83 (0.38)	3.92 (0.28)	3.85 (0.49)
Communication	3.41 (0.85)	3.40 (0.81)	3.36 (0.89)	3.40 (0.84)	3.61 (0.72)	3.72 (0.57)	3.69 (0.48)	3.70 (0.66)
RRB	3.20 (0.98)	2.60 (1.22)	3.35 (0.89)[a]	3.08 (0.98)	3.39 (0.80)[b]	3.56 (0.86)	3.62 (0.65)	3.45 (0.83)
Total	10.12 (1.96)	9.43 (2.06)	10.22 (1.87)	9.92 (2.18)	10.74 (1.63)	11.11 (1.64)	11.23 (1.24)	11.00 (1.49)
Autism discriminators	M(SD)	M(SD)	M(SD)	M(SD)	M(SD)	M(SD)	M(SD)	M(SD)
Social communication	0.78 (0.99)	0.80 (1.03)	0.57 (0.84)	0.83 (0.91)	1.48 (1.31)[c]	1.11 (1.13)	1.38 (1.39)	1.80 (1.40)[c]
RRB	1.68 (1.38)	1.40 (1.22)	1.69 (1.46)	1.62 (1.21)	1.97 (1.45)	1.94 (1.55)	2.46 (1.27)	2.15 (1.63)
Total	2.45 (1.94)	2.20 (1.75)	2.26 (1.93)	2.45 (1.68)	3.45 (2.32)[d]	3.06 (2.24)	3.85 (2.03)	3.95 (2.67)

[a] White > Hispanic, $p < .05$

[b] Somali > Hispanic, $p < .05$

[c] Somali > White, $p < .01$

[d] Somali > White, $p < .05$

The methodology employed in this study was not designed to address questions of causality, and additional research is needed to elucidate potential biological susceptibility and/or environmental factors that may contribute to the pattern of greater intellectual impairment among Somali children. Research is emerging in this area from studies that found similar patterns of high rates of ID among Somali and other immigrants with ASD. Magnusson et al. (2012) found that risk for ID with ASD was highest when pregnancies occurred within a year of migration, suggesting stressors specific to migration may contribute. Gathering data on timing of migration is a direction for future research. Further, vitamin D deficiency has been implicated as a possible risk factor for Somali children, as Somali mothers and their newborns were found to have markedly lower levels of vitamin D than children and mothers of Swedish, non-Scandinavian European, South American, and East Asian origin (Fernell et al. 2015). Vitamin D has been hypothesized to impact the serotonin system (Patrick and Ames 2014), and hyperserotonemia has been associated with ASD (Mulder et al. 2004).

A few researchers (Fairthorne et al. 2017; Magnusson et al. 2012) also have hypothesized that the relatively higher frequency of ASD with ID among children of immigrant families, and the low frequency of ASD without ID among these children, may result from bias in diagnostic procedures stemming from language barriers, lack of cultural knowledge, or practitioner bias. It is possible that cultural bias in assessments used as well as the unique challenges of valid intellectual assessment in children with ASD (Charman et al. 2005) could have influenced our findings. A marker of this could be the higher assignment of "cognitive impairment NOS" among Somali children compared to white children. This may reflect clinician reluctance to use standardized measures on populations for which the tests were not normed and for whom English may not be the primary language, which may have led to inaccurate conclusions about level of cognitive functioning.

Diagnostic substitution has been identified as a possible reason for observed increases in ASD prevalence over the past several decades (e.g., Volkmar et al. 2004), and there is some evidence from educational data that administrative prevalence of ASD rose as administrative prevalence of intellectual disability fell (Coo et al. 2008; Newschaffer 2006; Shattuck 2006). However, a study conducted in Minnesota did not detect a corresponding decrease in any special education disability category as ASD rose (Gurney et al. 2003). In Minneapolis, the phenomenon could be occurring in the opposite direction. Due to media coverage reporting high rates of ASD among Somali children, children with general intellectual disability could be getting misdiagnosed with ASD. Alternatively, practitioners may have failed to diagnose ASD in Somali children when it was not accompanied by intellectual disability. If true, it could indicate that Somali children may indeed have significantly higher rates of ASD compared to other racial/ethnic groups.

Cultural beliefs also may have influenced referral patterns. Cultural goals, beliefs, and attitudes influence the type and level of behaviors that are identified as

Table 5 Number and percentage of children identified with associated features by race/ethnicity and Somali status

	All ASD cases					ASD + ID (IQ ≤ 70)		
	Total ($N=234$)	Hispanic ($n=30$)	White ($n=120$)	Non-Somali black ($n=53$)	Somali ($n=31$)	White $n=18$	Non-Somali Black $n=13$	Somali $n=20$
Associated features	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Abnormal eating/drinking	140 (59.8)	21 (70.0)	63 (52.5)	31 (58.5)	25 (80.6)[a,b]	13 (72.2)	9 (69.2)	16 (80.0)
Abnormal sleeping	83 (35.5)	9 (30.0)	46 (38.3)	16 (30.2)	12 (38.7)	5 (27.8)	4 (30.8)	7 (35.0)
Abnormal mood/affect	215 (91.1)	26 (86.7)	113 (94.2)	48 (90.6)	28 (90.3)	16 (88.9)	12 (92.3)	19 (95.0)
Abnormalities in cognitive dev	72 (30.8)	10 (33.3)	44 (36.7)	13 (24.5)	5 (16.1)	5 (27.8)	1 (7.7)	2 (10.0)
Aggression	146 (62.4)	16 (53.3)	72 (60.0)	35 (66.0)	23 (74.2)	8 (44.4)	11 (84.6)	16 (80.0)
Argumentative/oppositional	198 (84.6)	25 (83.3)	101 (84.2)	42 (79.2)	30 (96.8)	12 (66.7)	9 (69.2)	19 (95.0)
Delayed motor functioning	178 (76.1)	22 (73.3)	91 (75.8)	38 (71.7)	27 (87.1)	15 (83.3)	9 (69.2)	18 (90.0)
Hyperactivity/attention problems	218 (93.2)	26 (86.7)	112 (93.3)	50 (94.3)	30 (96.8)	18 (100)	12 (92.3)	20 (100)
Lack or excessive fear	160 (68.4)	19 (63.3)	78 (65.0)	36 (67.9)	27 (87.1)	10 (55.6)	11 (84.6)	17 (85.0)
Odd response to sensory stimuli	210 (89.7)	25 (83.3)	111 (92.5)	47 (88.7)	27 (87.1)	16 (88.9)	11 (84.6)	18 (90.0)
Self injurious behavior	78 (33.3)	10 (33.3)	38 (31.7)	16 (30.2)	14 (45.2)	8 (44.4)	6 (46.2)	11 (55.0)
Staring spells/seizures	79 (33.8)	8 (26.7)	40 (33.3)	18 (34.0)	13 (41.9)	7 (38.9)	6 (46.2)	9 (45.0)
Temper tantrums	117 (50.0)	16 (53.3)	59 (49.2)	31 (58.5)	11 (35.5)	5 (27.8)	9 (69.2)	8 (40.0)
Mean total features (M, SD)	8.09 (2.31)	7.77 (2.51)	8.07 (2.34)	7.94 (2.42)	8.77 (1.69)	7.67 (3.07)	8.46 (3.07)	9.00 (1.52)

[a] Somali > white, $\chi^2 = 8.03$, p = .005, OR 3.77, 95% CI1.44–9.85

[b] Somali > non-Somali black, $\chi^2 = 4.32$, p = .038, OR 2.96, 95% CI 1.04–8.41

concerning, when parents choose to seek help, and, in general, how families experience ASD (Grinker et al. 2012; Mandell and Novak 2005; Ravindran and Myers 2012). It is possible that Somali families may not be reporting specific concerns to medical practitioners in cases where the child does not have significant delays in learning.

Culture also influences resources available for diagnosis and treatment, selection and efficacy of treatments, and the relationship between families and professionals (Ravindran and Myers 2012). The original MSASDPP study found that Somali children with ASD were as likely as white children to have been evaluated in both school and clinic settings (Hewitt et al. 2014). The MSASDPP did not collect data on services received after diagnosis. However, Somali families on average have a markedly low SES: 40% of Somali Minnesotans ages 16–64 are either unemployed or not participating in the labor force, and the median household income for Somali families is $18,600 (Minnesota State Demographic Center 2016). It is plausible, due to limited economic resources, that fewer Somali children received

early intensive behavior intervention, which has the most evidence in supporting positive outcomes for children with ASD (e.g., Dawson et al. 2010). In the Minneapolis area, early intensive behavior intervention is available and is covered by medical assistance (MA), but qualifying for MA coverage of these services requires several steps, including a clinic-based multidisciplinary evaluation, for which there is often a wait of several months to a year. In-home intervention services require that caregivers are available largely during business hours for therapy, which typically is 25–40 h a week, which could constrain work schedules. Similar logistic and economic barriers could lead to less access to private therapies for Somali children, such as speech-language and occupational therapy. In a qualitative study of Somali, Hmong, and Latino families' experiences with ASD in Minnesota (Minnesota Department of Health 2014), Somali families identified the following as barriers to obtaining services: difficulties juggling finding services for their child with work and the needs of other children in their family, lack of knowledge about services and resources available, stigma, and difficulties finding safe housing. Reduced access to intensive intervention may be a factor worth exploring regarding the higher proportion of ASD with intellectual disability among Somali children; however, it is important to note that comprehensive behavioral and developmental interventions designed for children with ASD have not been studied in Somali or other diverse cultural groups, either in their cultural appropriateness or in their efficacy (Bernier et al. 2010).

ASD Symptom Profiles Across Racial/Ethnic Groups

Regarding differences in ASD symptom profiles, our findings were consistent with the majority of studies that have not found differences in autism symptomatology across racial/ethnic groups based on DSM-IV criteria (Cuccaro et al. 2007; Lord et al. 2006; Stronach 2013; Tek and Landa 2012). A few differences in symptom frequencies and in the proxies used for severity were present across the whole sample, but in most cases, patterns of symptom endorsement were similar across racial/ethnic groups. When the sample was limited to children with ASD with intellectual disability and sample sizes were large enough to detect differences, no significant differences were found. This is especially important, because most group differences within the full sample occurred in the direction of Somali children showing higher frequencies of individual symptom endorsement and greater total number of symptoms than other groups. These findings suggest that level of cognitive impairment may have been driving these differences and point to the difficulties in separating ASD symptom severity from functional impairment (Weitlauf et al. 2014).

Although best practices for diagnostic evaluation of ASD have been described (e.g., Esler and Ruble 2015; Filipek et al. 1999; Huerta and Lord 2012), scant attention has been given to the accuracy and applicability of current diagnostic measures and schema in culturally and linguistically diverse children. It is unknown whether findings of few differences in symptom presentation across racial/ethnic groups result from possible biases in measures or a lack of actual differences in symptoms. Perhaps there are important symptoms of ASD that differ across cultures but that are not being detected by existing measures. Harris et al. (2014) reviewed research on currently used diagnostic and screening measures regarding their inclusion of cultural considerations. Most measures included culturally diverse groups in the norming samples; however, only two screening tools (the Modified Checklist for Autism in Toddlers and the Social Communication Questionnaire) included limited English proficient samples. None of the measures included standardized methods for modifying or adapting test administration for culturally diverse families, although a couple offered suggestions for modifications. Along these lines, in a study of ASD in South Africa, focus groups were held in a Zulu community that evaluated the cultural appropriateness of 193 statements and questions culled from standardized instruments for ASD, which included the Autism Diagnostic Observation Schedule (Lord et al. 2000) and the Communication and Symbolic Behavior Scales (Wetherby and Prizant 2002). As a result of this process, a significant minority, 36%, of 193 items were revised to improve clarity and simplicity of wording, replace English idiomatic expressions, and eliminate or replace content that was not culturally relevant (Grinker et al. 2012). It is possible that, without modifications informed by cultural context, true differences in phenotype could be missed.

Associated Features Across Racial/Ethnic Groups

In our study, Somali children were more likely than white and non-Somali black children to have abnormal eating/drinking. Again, the reasons for these differences could either reflect true differences in symptom presentation or cultural differences related to reporting eating/drinking skills or to different expectations for child behavior. Associated features of inattention/hyperactivity, mood problems, oppositional behavior, and unusual responses to sensory stimuli were commonly reported in all children's records across racial/ethnic groups. In contrast, few children from any racial/ethnic group were identified as having sleep problems, which is inconsistent with literature indicating a high correlation between ASD and sleep issues (Krakowiak et al. 2008; Sivertsen et al. 2012). This may be related to data source. Studies reporting high rates of sleep problems in ASD tended to involve parent interview or survey data in

which participants were directly asked about sleep. Sleep patterns may not be as relevant to educational evaluations or diagnostic assessments, which were the sources of data for the present investigation.

Rates of reported developmental regression in the current study sample (~14%) also were lower than those previously reported, including within studies using similar methodology (Wiggins et al. 2009). Previous investigations have reported approximately one-third to one-half of children with ASD experience regression (Hansen et al. 2008; Goin-Kochel et al. 2014; Lord et al. 2004; Wiggins et al. 2009). Further, some research suggests that children from diverse communities experience higher rates of developmental regression than white children (Spinks-Franklin et al. 2014). Explanations for this finding are not clear but could reflect differences in diagnostic tools and practices used in the Minneapolis metropolitan area rather than an actual difference in rates of regression.

Limitations

Several limitations are important to mention. The surveillance area included in this study was Minneapolis, and findings only represent the Minneapolis community and are not representative of other communities in Minnesota or the United States as a whole. It is also important to note that the findings represent the calendar year 2010 for children age 7–9 years and may not generalize to other years or age groups.

The surveillance activities did not result in 100% case ascertainment, so findings may represent an underestimate of prevalence. It was not possible to get 100% case ascertainment because of the requirement by Minneapolis Public Schools to provide passive consent to parents/legal representatives and due to the inability to review records in all charter schools and clinics serving Minneapolis children. The majority of records excluded by the passive consent process were a result of being returned undeliverable rather than parents electing not to participate. This suggests the potential for bias in this sample, as families who are highly mobile are more likely to have a lower socioeconomic status and are more likely to be non-white (Minnesota State Demographic Center 2016).

The surveillance methods used in this project relied on the review of administrative records from clinics and educational institutions, and results are limited to the information included in those records. Fidelity and reliability of the evaluations that yielded the records are unknown variables that could have influenced the validity of the findings. ASD case status was not confirmed via direct assessment. Although the records reviewed were comprehensive and often contained standardized diagnostic measures, such as the ADOS (Lord et al. 2000), there may have been information relevant to diagnosis that was not included in records reviewed.

Another challenge to this study related to the difficulties in identifying Somali status. Children were identified as Somali mainly based on primary language spoken in the home, as this was determined to be the most reliable indicator of Somali background. This may have resulted in under-identification of Somali children whose families spoke a language other than Somali or whose records did not include information on language spoken in the home.

With a relatively small number of participants, the clinical presentation of ASD among Somali children in this study may not generalize to ASD presentation in the overall population of Somali children, and additional research conducted with larger samples and within a wider geographic area is needed. Moreover, caution is warranted because there was not cognitive data on 100% of the study sample. However, proportions of children in the current study who had IQ scores or other cognitive information included in their records were similar to those in other sites within the CDC ADDM Network (CDC 2016a) and did not differ statistically across racial/ethnic groups. Confirmation of these findings through direct assessment of Somali children is needed both to verify their accuracy and to explore the utility of current diagnostic instruments in identifying ASD within this cultural group. Further research also is needed to investigate potential bias in standardized cognitive measures among typically developing Somali students to help clarify results of the current investigation.

Although this paper has focused mainly on Somali children, the above recommendations for future research are applicable to other racial/ethnic groups. The lower prevalence of ASD among Hispanic and non-Somali black children and the extremely low number of Asian and Native American children with ASD in our sample are reminders that health disparities in access to diagnosis exist and need to be better understood.

Conclusion

Results of this study lend further support to concerns that children of immigrants and refugees from low human resource index countries, and Somali children in particular, are being identified more frequently with ASD with intellectual disability than are other groups. This study also found few differences overall in the presence of specific ASD symptoms and associated features across race and ethnicity once cognitive level was controlled. Because the purpose of the project was public health surveillance, this study was not designed to answer questions about why these differences, or lack thereof, exist. Regardless, it is clear that interventions in the Somali diaspora and other, similar populations should target both the unique and

shared intervention needs of both ASD and intellectual disability. The increased level of functional impairment highlights the urgency for early intervention, comprehensive intervention, and provision of intervention and support services across the lifespan.

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Author Contributions ANE conceived of the study, participated in its design and coordination, performed the statistical analyses and interpreted the data, and drafted the manuscript. JHL participated in the design and coordination of the study, participated in interpretation of the data, and helped to draft the manuscript. AH conceived of the study, participated in its design and coordination, participated in interpretation of the data, and helped to draft the manuscript. All authors read and approved the final manuscript.

Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

Informed Consent This article does not contain any studies with human participants performed by any of the authors. This study was a surveillance study of clinic and special education records. There was no direct contact with study participants. However, a passive (informed consent) process was included in the study in which a letter was sent home and families could decline participation.

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