






# Ethnic Disparities in the Diagnosis of Autism in Southern Israel

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The prevalence of autism spectrum disorder (ASD) is continuously rising worldwide, with remarkable differences in ASD rates being reported across ethnic and socioeconomic groups. We conducted a prospective cohort study to identify the reasons for differences in ASD rates between the Bedouin and Jewish populations in southern Israel. Screening, referral, and diagnosis of toddlers aged 16–36 months were compared between Bedouin and Jewish populations. ASD screening was conducted at 35 randomly selected mother and child health centers (MCHCs) by trained nurses using the Modified Checklist for Autism in Toddlers with follow-up (M-CHAT/F) instrument. Toddlers screened positive at the MCHCs were monitored throughout the referral and diagnosis process at a single medical center until a diagnosis was determined by a physician specialist using DSM-5 criteria. The study cohort comprised 3,343 toddlers (996 Jewish and 2,347 Bedouin). Bedouin toddlers, compared to Jewish toddlers, were less likely to screen positive with M-CHAT/F (3.0% vs. 3.9%;  $P = 0.165$ ), were significantly less likely to begin the hospital diagnosis process (HR = 0.38, 95% CI: 0.14–1.08;  $P = 0.068$ ), and had a higher rates of loss-to-follow-up during the hospital diagnosis process (42.9% vs. 15.6%, respectively;  $P = 0.001$ ). The results suggest that ethnic-specific barriers in the diagnosis process of ASD contribute to under-diagnosis of ASD in the Bedouin population. Facilitating the diagnosis process for Bedouin families will help to identify more children with ASD at earlier ages and consequently close the ethnic gap in ASD rates. *Autism Res* 2020, 00: 1–9. © 2020 International Society for Autism Research and Wiley Periodicals LLC

**Lay Summary:** We followed Bedouin and Jewish toddlers aged 16–36 months from southern Israel through their autism spectrum disorder (ASD) screening referral and diagnosis to identify the reasons for the differences in ASD prevalence between these ethnic groups. Jewish and Bedouin toddlers were equally identified in the ASD screening. However, Bedouin toddlers were less likely to complete the diagnosis process due to higher rates of loss-to-follow-up and slower diagnosis process. Facilitating ASD diagnosis for the Bedouin population will help identifying more toddlers with ASD.

**Keywords:** autism spectrum disorder; ethnic disparities; autism diagnosis; access to healthcare

## Introduction

Prevalence rates of autism spectrum disorder (ASD) have increased remarkably in the past few decades; for example, in the United States, these rates rose from approximately one affected child per 10,000 births in 1970 [Treffert, 1970] to one in 59 children in 2014 [Baio et al., 2018]. Similar increases in ASD prevalence have been reported worldwide, albeit with marked inter-country variability [Christensen et al., 2016; Elsabbagh et al., 2012]. This massive increase in prevalence rates has been attributed largely to improved awareness of the disorder among parents, caregivers, and physicians [Kogan et al., 2018; Leonard et al., 2010] – an awareness that typically has a greater impact on high-income populations. Indeed, several studies that have been conducted in the

United States found the prevalence of ASD to be lower among children of families with lower socioeconomic status (SES), with the prevalence increasing steadily with higher SES [Dickerson et al., 2017; Durkin et al., 2017; Kelly et al., 2017; Kuehn, 2012]. ASD rates also vary between racial and ethnic groups in the United States [Braun et al., 2015; Durkin et al., 2017; Durkin et al., 2010; Maenner, Arneson, & Durkin, 2009; Mandell et al., 2009; Wiggins et al., 2019; Zablotsky et al., 2019]. For example, national surveys have shown the reported prevalence of ASD to be comparable for African-American and White children and to be significantly lower for Latinos than for non-Latinos [Croen, Grether, & Selvin, 2002; Durkin et al., 2017; Wiggins et al., 2019; Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015; Zuckerman et al., 2017]. It appears that the reasons

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underlying these observed differences in ASD rates are manifold: cultural differences in recognizing the symptoms of autism [Begeer, Bouk, Boussaid, Terwogt, & Koot, 2009; Matson et al., 2011], differences in parental knowledge and/or language barriers [Zuckerman et al., 2017], dissimilarities in the sensitivity of ASD screening instruments for children of different ethnicities [Rea, Armstrong-Brine, Ramirez, & Stancin, 2019], and differences in access to healthcare services [Liptak et al., 2008].

In Israel, like in many other countries in the world, the incidence of ASD is continuously increasing in the last two decades [Davidovitch, Hemo, Manning-Courtney, & Fombonne, 2013; Raz, Weisskopf, Davidovitch, Pinto, & Levine, 2015]. Yet, the reported prevalence of ASD varies according to geographic regions, ethnic populations, and SES. For example, it has been shown that the prevalence of ASD among Arabs and Ultra-Orthodox Jews being significantly lower than that in the general population [Davidovitch et al., 2013; Segev, Weisskopf, Levine, Pinto, & Raz, 2019]. In addition, a recent study reported that ASD in Israel is positively associated with yearly household income, and this is true for different ethnic groups [Segev et al., 2019]. Finally, ASD prevalence in Israel also vary according to geographic region with the highest prevalence was reported for the central region of the country compared the southern and northern regions of the country [Kerub, Haas, Menashe, Davidovitch, & Meiri, 2018].

The population of southern Israel – the Negev region – comprises two major ethnic groups, Jews and Bedouin Arabs [The Central Bureau of Statistics of Israel, 2018c]. Births in this region number approximately 16,000 per year, distributed evenly between these two populations [The Central Bureau of Statistics of Israel, 2018b]. Nonetheless, the number of children diagnosed with ASD in the Jewish population is four times higher than that in the Bedouin population [Meiri et al., 2017]. The reasons for this marked ethnic difference in ASD rates in southern Israel could stem from under-diagnosis in the Bedouin population, as previously suggested [Levaot, Meiri, Dinstein, Menashe, & Shoham-Vardi, 2019; Mahajnah et al., 2015], or over-diagnosis in the Jewish population, or they could, indeed, be due to real differences in ASD prevalence between these populations. To resolve this issue, we conducted a prospective cohort study of these two populations in which toddlers between the ages of 16 and 36 months were screened for signs of ASD by using the Modified Checklist for Autism in Toddlers (M-CHAT) instrument [Robins, Fein, Barton, & Green, 2001] with follow-up (M-CHAT/F) [Dumont-Mathieu, 2017] until completion of diagnosis process. The rates for the two populations were compared at different key points along the diagnosis process, as were the times between the different stages of the diagnosis.

The study received ethics approval from the Research Ethics Boards of the Soroka University Medical Center (SUMC) and the Israel Ministry of Health.

## Methods

### *Study Design and Participants*

The development of newborns in southern Israel is routinely monitored from birth until the age of 6 years at 47 mother and child health centers (MCHCs) distributed across the region. Attendance at these MCHCs is extremely high, with 95–99% of all newborns attending MCHCs for developmental assessments, vaccinations, and other services during infancy [Ministry of Health, Southern Health District, and Israel Center for Disease Control, 2008]. We conducted a prospective cohort study of toddlers aged 16–36 months attending their regular developmental assessment visits at 35 of these MCHCs selected at random. We included in the study only toddlers who are members of Clalit Health Services, the largest health maintenance organization (HMO) in Israel, which provides health services to ~75% of the population of southern Israel. This inclusion criterion was applied because members of the Clalit HMO obtain primary health services (including child developmental assessments) at SUMC, which is the only tertiary hospital in this region.

### *ASD Screening*

Nurses employed at the MCHCs were trained to administer the M-CHAT questionnaire with 23 yes/no items [Robins et al., 2001], since at the time of the study there were no Hebrew or Arabic translations of newer versions of this tool. Screening for ASD was conducted between March 2015 and December 2017 by these trained nurses who administered the M-CHAT questionnaire in addition to routine developmental screening, as described by Kerub et al. [Kerub, Haas, Meiri, Davidovitch, & Menashe, 2018]. Toddlers who screened positive with the M-CHAT questionnaire were followed up by an ASD specialist nurse using the M-CHAT follow-up (M-CHAT/F) questionnaire [Robins et al., 2001]. Toddlers who screened positive with M-CHAT/F were then referred to their pediatrician to receive a formal referral form for a developmental evaluation at the hospital as required by Israeli HMOs.

### *ASD Diagnosis*

The developmental assessment of all children in this study was made at SUMC. This process included assessment with the Autism Diagnostic Observation Scale-second edition (ADOS-2) test [Lord et al., 2000] and cognitive evaluation using either the Bayley Scales of Infant

and Toddler Development—third edition (Bayley-3) [Bayley, 2006] or the Wechsler Preschool and Primary Scale of Intelligence – version three (WPPSI-3) [Wechsler, 1991]. In addition, the families of these toddlers met with social workers, developmental psychologists, and expert physicians (a child psychiatrist or a child neurologist), who eventually provided a diagnosis according to the criteria of the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5) [American Psychiatric Association, 2013]. At the end of the diagnostic process, which typically included one to four visits to SUMC, one of the following diagnoses was made: (a) ASD; (b) developmental delay (DD) or a specific developmental disorder of speech and language; or (c) typical development (TD).

### *Assessment of Population Differences*

Differences in ASD prevalence may stem from any of the three critical stages of ASD diagnosis: (a) the screening; (b) the referral process (HMOs in Israel require a formal referral from a pediatrician before a child evaluated by a nurse at an MCHC can be referred to a hospital); and (c) the diagnosis process at the hospital. We examined differences between the Jewish and Bedouin populations in rates of toddlers involved in each of these processes by using standard univariate statistics (e.g., *t*-test, Chi-Square test). In addition, we used Kaplan–Meier analysis and Cox regression models to examine differences between these two ethnic groups in completing different stages in the referral and diagnosis processes.

## **Results**

### *Sample Characteristics*

Overall, 3,343 toddlers (996 Jewish and 2,347 Bedouin) were included in this study. Key characteristics of the study cohort are depicted in Table 1. There was a slight over-representation of males in the cohort, with no significant differences between Jewish and Bedouin toddlers (55.0% vs. 53.9%, respectively;  $P = 0.552$ ). However, the Bedouin toddlers were, on average, 1 month older than Jewish toddlers at the time of screening ( $21.5 \pm 3.9$  vs.  $20.3 \pm 3.2$  months, respectively;  $P < 0.001$ ), and this age difference increased to  $>3.5$  months for toddlers who screened positive in the MCHAT/F test ( $23.8 \pm 5.0$  vs.  $20.2 \pm 3.4$  months, respectively;  $P < 0.001$ ). In addition, Bedouin toddlers had a significantly lower SES than Jewish toddlers (Median SES of 1 vs. 4–5, respectively;  $P < 0.001$ ).

### *Population Differences in Referral and Diagnosis*

Twelve of the 996 Jewish toddlers but only ten of the 2,347 Bedouin toddlers in the cohort were diagnosed

with ASD, resulting in a threefold difference in the ASD prevalence between these two populations (1.2%, 95% CI: 0.5%–1.9% vs. 0.4%, 95% CI: 0.1%–0.7%, respectively). Similar ethnic differences in the cohort were found for toddlers diagnosed with other types of DD, with 12/996 and 16/2347 such diagnoses for Jewish and Bedouin toddlers, respectively (1.2%, 95% CI: 0.5%–1.9% vs. 0.7%, 95% CI: 0.4%–1.09%, respectively). To identify possible reasons for these marked ethnic differences, we compared the rates of toddlers completing key stages in the diagnosis process, as depicted in Figure 1. Of the 3,343 toddlers who were screened with the M-CHAT/F instrument, 109 (3.3%) screened positive, with slightly higher rates for Jewish toddlers, although the difference was not statistically significant (3.9% vs. 3.0%, respectively;  $P = 0.165$ ). Of the 109 toddlers who were referred for further developmental assessment at SUMC, 88 (80.7%) started the diagnosis process and 59 of these (67%) completed it during the time course of the study. While there were no ethnic differences in the rates of toddlers who started the diagnosis process (82.1% vs. 80.0% for Jewish and Bedouin toddlers, respectively;  $P = 0.795$ ), only 57.1% of the Bedouin toddlers completed the diagnosis process during the course of this study compared to 84.4% of the Jewish toddlers ( $P = 0.001$ ). Finally, there were no significant differences in the types of diagnosis (i.e., ASD, DD, or TD) made for Jewish and Bedouin toddlers who completed their diagnosis process during this study ( $P = 0.512$ ), nor in the ASD severity of these two groups (Table 2).

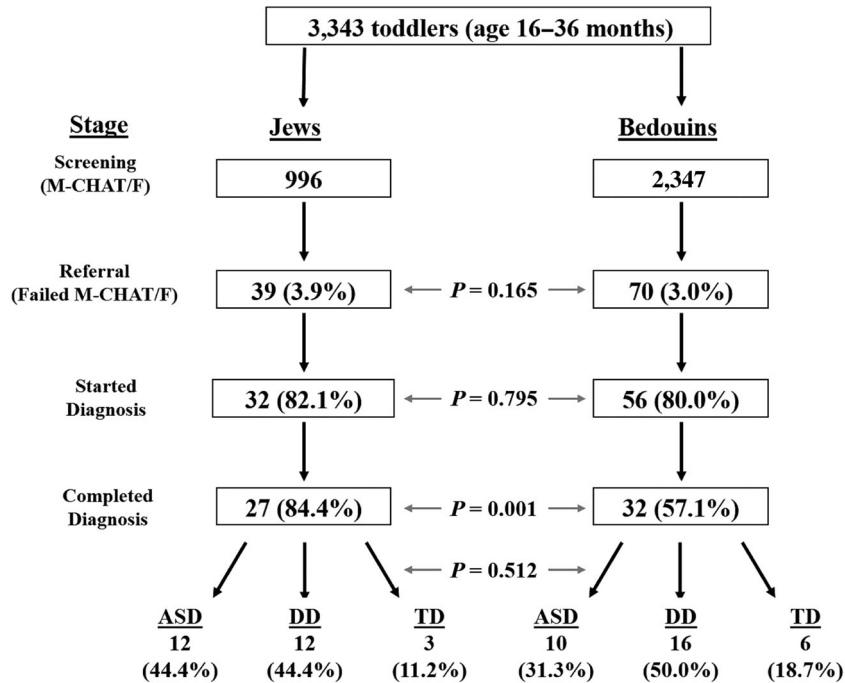
We also used Kaplan–Meier analyses to examine population differences for time intervals between key referral and diagnosis stages (Table 3; Fig. S1). The median time from referral until diagnosis completion was 11 months (95% CI: 9.0–13.0) with no significant differences between Jewish and Bedouin toddlers (median = 11, 95% CI: 7.7–14.3 vs. median = 12, 95% CI: 9.3–14.7 months, respectively;  $P = 0.269$ ). However, there were significant differences in the time from referral until diagnosis between toddlers who were eventually diagnosed with ASD to those who did not (median = 29, 95% CI: 12.2–45.8 vs. median = 13, 95% CI: 11.5–14.5 months, respectively;  $P = 0.039$ ) and these difference were seen only in the Bedouin population. Next, we divided the follow up time to the “referral period” (i.e., the time from referral at the MCHC until the first diagnosis meeting at SUMC) and to the “diagnosis period” (i.e., the time from the first diagnosis meeting at SUMC until diagnosis completion). Repeating these analyses in these two periods revealed significant ethnic differences in referral time between Jewish and Bedouin toddlers with ASD ( $P = 0.007$ ) and in diagnosis time between ASD and non-ASD toddlers, which were statistically significant only among the Bedouin population ( $P = 0.042$ ). Finally, we used cox regression models to assess the hazard ratios for

**Table 1. Key Characteristics of the Study Sample**

Stage	Variable	Jewish	Bedouin	P-value
Screening	Total # of toddlers	996	2347	-
	Age (months) <sup>a</sup>	20.3 ± 3.2	21.5 ± 3.9	<0.001
	Gender (males)	548 (55.0%)	1265 (53.9%)	0.554
	SES, median (range) <sup>b</sup>	5 (3–9)	1 (1–5)	<0.001
	Total # of toddlers	39	70	-
	Age (months) <sup>a</sup>	20.2 ± 3.4	23.8 ± 5.0	<0.001
Referral	Gender (males)	25 (64.1%)	48 (68.6%)	0.632
	SES, median (range) <sup>b</sup>	4 (3–5)	1 (1–5)	<0.001
	Total # of toddlers	32	56	-
Started diagnosis	Age (months) <sup>a</sup>	20.3 ± 3.5	24.6 ± 5.0	<0.001
	Gender (males)	18 (56.6%)	39 (69.6%)	0.206
	SES, median (range) <sup>b</sup>	4 (3–5)	1 (1–5)	<0.001
	Total # of toddlers	27	32	-
Completed diagnosis	Age (months) <sup>a</sup>	20.6 ± 3.7	24.5 ± 5.6	0.002
	Gender (males)	14 (41.2%)	20 (58.8%)	0.410
	SES, median (range) <sup>b</sup>	4 (3–5)	1 (1–4)	<0.001

<sup>a</sup>Age at screening.

<sup>b</sup>Socioeconomic status (SES) was determined by the residence of child according to The Central Bureau of Statistics of Israel (2018a).



**Figure 1.** Rates for toddlers at different screening and diagnosis stages in this study. The rates for Jewish and Bedouin toddlers were compared across four key screening and diagnosis stages investigated in this study. P-values indicate the statistical significance of ethnic disparities in each of these stages. ASD: autism spectrum disorder; DD: other types of developmental delay; TD: typical development.

completion the different referral and diagnosis stages, which are associated with Bedouin ethnicity and ASD diagnosis while adjusting for the SES and age of the toddlers in the study (Table S1). The most significant findings in these analyses suggest that Bedouin toddlers are approximately three times less likely to start the diagnosis process than Jewish toddlers (HR = 0.38, 95% CI: 0.14–1.08;  $P = 0.068$ ).

## Discussion

The overall prevalence of ASD in this study was 0.76%, which is higher than that previously reported for the southern region of Israel [Kerub, Haas, Menashe, et al., 2018; Levaot et al., 2019]. This increase in ASD prevalence is in keeping with the general trend of increasing ASD rates in Israel [Davidovitch et al., 2013; Raz

**Table 2. ASD Severity Measures**

	Jewish (n = 12)	Bedouin (n = 10)	P-value
IQ, mean ± SD	78.2 ± 15.5	75.8 ± 13.3	0.663
ADOS-2 comparison score, mean ± SD <sup>a</sup>	7.4 ± 2.8	6.9 ± 2.4	0.578
DSM-5 severity (A category), n (%) <sup>b</sup>	Requiring support	0 (0.0)	0.626
	Requiring substantial support	4 (33.3)	
	Requiring very substantial support	6 (50.0)	
	Requiring support	1 (8.3)	
DSM-5 severity (B category), n (%) <sup>b</sup>	Requiring substantial support	6 (60.0)	0.626
	Requiring very substantial support	4 (40.0)	
	Requiring support	0 (0.0)	

<sup>a</sup>For more information, please see Lord et al. [2000].

<sup>b</sup>For more information, please see American Psychiatric Association [2013].

**Table 3. Ethnic Differences in Referral and Diagnosis**

Time interval	Group	All		Jewish		Bedouin		P-value <sup>a</sup>
		Median (months)	95% CI (median)	Median (months)	95% CI (median)	Median (months)	95% CI (median)	
Referral to diagnosis	All <sup>b</sup>	11	9.0–13.0	11	7.7–14.3	12	9.3–14.7	0.269
	ASD	29	12.2–45.8	14	2.9–8.3	>22	-	0.184
	Non-ASD	13	11.5–14.5	14	10.6–17.4	13	11.8–14.2	0.741
	P-value <sup>c</sup>	<b>0.039</b>		0.992		<b>0.008</b>		
Referral to first visit	All <sup>d</sup>	4	2.5–5.5	2	0.0–4.3	5	2.9–7.1	0.131
	ASD	13	11.3–14.6	6	1.9–10.7	>20	-	<b>0.007</b>
	Non-ASD	12	9.1–14.9	8	5.1–10.9	12	8.7–15.3	0.348
	P-value <sup>c</sup>	0.690		0.352		0.548		
First visit to diagnosis	All <sup>b</sup>	4	2.2–5.8	3	0.6–5.4	4	1.6–6.4	0.695
	ASD	12.0	2.0–22.0	8	1.7–14.2	>18	-	0.352
	Non-ASD	8	4.7–11.3	8	2.9–13.0	8	2.9–13.1	0.770
	P-value <sup>c</sup>	0.212		0.545		<b>0.042</b>		

<sup>a</sup>Log-Rank test for survival time comparison between Jewish and Bedouin toddlers.

<sup>b</sup>All children who completed the diagnosis process.

<sup>c</sup>Log-Rank test for survival time comparison between ASD and non-ASD toddlers.

<sup>d</sup>All children who attended the first visit.

et al., 2015]. Furthermore, the implementation of the M-CHAT/F instrument, which has been shown to be more effective in detecting toddlers with ASD than the previously used Global Developmental Screening (GDS) instrument [Kerub, Haas, Meiri, et al., 2018], could also contribute to the increase in ASD prevalence in this study. As previously reported [Levaot et al., 2019], in this study, ASD prevalence in the Jewish population was three times higher than that in the Bedouin population. Nevertheless, toddlers with ASD in these two ethnic groups had similar ASD severity measures suggesting that ASD severity is unlikely a contributing factor to the difference in ASD prevalence between Bedouin and Jewish toddlers. We identified three possible factors that could explain this ethnic difference, as discussed below.

#### *Ethnic Disparity in ASD Screening*

We found that Jewish toddlers were more likely to screen positive with the M-CHAT/F than Bedouin toddlers,

although this difference was not statistically significant ( $P = 0.165$ ). It is unlikely that this difference, if indeed real, is due to language barriers, since the M-CHAT questionnaires and follow-up screening evaluations were administered by trained nurses who spoke the language of the subjects. Nonetheless, the Arabic-speaking nurses who participated in this study reported that some of the M-CHAT questions (e.g., “Does your child enjoy playing peek-a-boo/hide-and-seek?”) were less relevant to the culture and daily life of the Bedouin families. In addition, it is possible that Bedouin families whose toddlers screened positive with the M-CHAT questionnaire were less likely to continue the follow-up step of the screening, in keeping with previous reports for other low SES racial minorities [Guthrie et al., 2019; Khowaja, Hazzard, & Robins, 2015]. Finally, the difference between Bedouin and Jewish toddlers in M-CHAT/F positive screening could reflect a small, but real, difference in actual ASD prevalence between these two genetically and culturally distinct populations living in southern Israel.

### *Ethnic Disparity in the Referral Process*

As mentioned above, the time interval between M-CHAT/F positive screening and initiation of diagnosis process at SUMC was significantly longer for Bedouin than Jewish families. Interestingly, this difference was specific to toddlers with ASD and was not seen in other toddlers. Since Israeli HMOs require a formal referral from a pediatrician for a developmental evaluation at a hospital, children who screened positive with the M-CHAT/F had to schedule a visit with their pediatrician before requesting an appointment for a hospital evaluation. Such an additional step in the referral process, which involves scheduling an additional visit to the clinic, may be more complicated for Bedouin families with difficulties in accessing health services [Southern et al., 2015] and hence lead to a higher dropout rate in this ethnic group.

Other factors that could have contributed to the ethnic differences in the referral process in this study were discrepancies on the part of the referring pediatricians. It is possible that pediatricians who serve in the clinics in the Bedouin community were less likely to refer children with suspected ASD to SUMC for further evaluation [Gabis & Raz, 2010]. Unfortunately, we did not have data regarding the visits of these children to their pediatricians or the outcomes of these visits. It is noteworthy, however, that no such differences in hospital evaluation rates were found for children with DD who face the same referral process. Thus, a more likely explanation for the discrepancy in the hospital evaluation rates was that Bedouin families of children with ASD were less likely to approach their pediatricians for a referral to the hospital. This notion is in keeping with prior studies that have indicated that subtle autistic symptoms may be undetected or presumed to be unimportant by parents of toddlers belonging to minority populations and that more significant symptoms are needed to prompt a search for intervention services [Cuccaro et al., 2007; Tek & Landa, 2012].

### *Ethnic Disparity in ASD Diagnosis*

We also found a higher rate of loss-to-follow-up for the Bedouin toddlers during the diagnosis process at SUMC. This difference could be attributed to the lack of public transportation to and from the unrecognized villages (villages not recognized as legal or supported by the State of Israel) where many of the Bedouin families live, which complicates their attendance at the multiple diagnosis meetings at SUMC [Zuckerman et al., 2017]. This is particularly relevant to children with ASD in which their diagnosis process is usually longer than other children as implied by our data. In addition, cultural and linguistic barriers may also contribute to the difficulties of Bedouin families in scheduling hospital diagnosis meetings. These

unique difficulties of the Bedouin population of the Negev have already been reported as factors that may contribute to impairment of the quality of care for this population, to damage to the therapeutic continuum, and potentially also to complicating the detection and diagnosis of ASD in the children of this population [Manor-Binyamini & Shoshana, 2018].

### *Study Advantages and Limitations*

This is the first study in Israel to follow toddlers from ASD screening through the diagnosis processes until ASD or other diagnoses are made. The fact that SUMC is the only hospital in southern Israel where toddlers with suspected ASD are definitely diagnosed is the biggest advantage of our study, since it means that it is very unlikely that loss-to-follow-up toddlers in the study have been diagnosed at other clinics. However, there are a few limitations that prevented us from drawing more robust conclusions. First, the moderate sample size of this study limited its power to identify mild ethnic differences in ASD screening and diagnosis. Specifically, a difference of ~30% in positive M-CHAT/F screening for ASD for Jews as compared to Bedouins was not statistically significant at  $\alpha < 0.05$ . A prospective power analysis indicates that the statistical power to declare such 30% difference as statistically significant at  $\alpha < 0.05$  in our sample is only 23.5%. In addition, our study was conducted with information obtained from four key stages during the screening and diagnosis processes. Increasing the number of follow-up points could increase the resolution of our analysis and allow us to gain more specific insights regarding the reasons for the ethnic disparities observed in the study. Finally, we did not obtain the views of the toddler's parents or of the healthcare providers regarding obstacles they encountered during the screening and diagnosis process. Such data could throw light on additional causes underlying the ethnic disparities in ASD diagnosis in southern Israel.

### **Conclusions**

Our results suggest that the notable differences in ASD rates between Bedouin and Jewish children in southern Israel are probably due to difficulties of the Bedouin families during the referral and diagnosis processes. This finding is consistent with literature suggesting that individuals across diverse backgrounds are uniformly affected by ASD [Fombonne, 2003] and that "prevalence disparities are more likely artifacts of historical inequities in the ASD identification process" [Khowaja et al., 2015]. Making ASD diagnosis more accessible to socioeconomically disadvantaged communities is likely to reduce ethnic disparities in ASD diagnosis.

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## Conflict of Interest

The authors have no conflicts of interest to disclose.

## Abbreviations

ADOS-2	Autism Diagnostic Observation Scale-second edition
ASD	autism spectrum disorder
DD	developmental delay
DSM-5	Diagnostic and Statistical Manual of Mental Disorders-fifth edition
M-CHAT/F	Modified Checklist for Autism in Toddlers with Follow-Up
MCHC	mother and child health centers
SES	socioeconomic status
SUMC	Soroka University Medical Center
TD	typical development

## References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders, fifth edition (DSM-V)*. Arlington, TX: American Psychiatric Association.
- Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., ... Dowling, N. F. (2018). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *Morbidity and Mortality Weekly Report: Surveillance Summaries*, 67(6), 1–23. <https://doi.org/10.15585/mmwr.ss6706a1>
- Bayley, N. (2006). Bayley scales of infant and toddler development—third edition. *Journal of Psychoeducational Assessment*, 25(2), 180–190. <https://doi.org/10.1177/0734282906297199>
- Begeer, S., Bouk, S. E., Boussaid, W., Terwogt, M. M., & Koot, H. M. (2009). Underdiagnosis and referral bias of autism in ethnic minorities. *Journal of Autism and Developmental Disorders*, 39(1), 142–148. <https://doi.org/10.1007/s10803-008-0611-5>
- Braun, K. V. N., Christensen, D., Doernberg, N., Schieve, L., Rice, C., Wiggins, L., ... Yeargin-Allsopp, M. (2015). Trends in the prevalence of autism spectrum disorder, cerebral palsy, hearing loss, intellectual disability, and vision impairment, metropolitan Atlanta, 1991–2010. *PLoS One*, 10(4), e0124120.
- Christensen, D. L., Baio, J., Van Naarden Braun, K., Bilder, D., Charles, J., Constantino, J. N., ... Yeargin-Allsopp, M. (2016). Prevalence and characteristics of autism spectrum disorder among children aged 8 years – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. *Morbidity and Mortality Weekly Report: Surveillance Summaries*, 65(3), 1–23. <https://doi.org/10.15585/mmwr.ss6503a1>
- Croen, L. A., Grether, J. K., & Selvin, S. (2002). Descriptive epidemiology of autism in a California population: Who is at risk? *Journal of Autism and Developmental Disorders*, 32(3), 217–224.
- Cuccaro, M. L., Brinkley, J., Abramson, R. K., Hall, A., Wright, H. H., Hussman, J. P., ... Pericak-Vance, M. A. (2007). Autism in African American families: Clinical-phenotypic findings. *American Journal of Medical Genetics Part B: Neuro-psychiatric Genetics*, 144(8), 1022–1026.
- Davidovitch, M., Hemo, B., Manning-Courtney, P., & Fombonne, E. (2013). Prevalence and incidence of autism spectrum disorder in an Israeli population. *Journal of Autism and Developmental Disorders*, 43(4), 785–793. <https://doi.org/10.1007/s10803-012-1611-z>
- Dickerson, A. S., Rahbar, M. H., Pearson, D. A., Kirby, R. S., Bakian, A. V., Bilder, D. A., ... Slay Wingate, M. (2017). Autism spectrum disorder reporting in lower socioeconomic neighborhoods. *Autism*, 21(4), 470–480. <https://doi.org/10.1177/1362361316650091>
- Dumont-Mathieu, T. (2017). Use of the M-CHAT follow-up interview (M-CHAT/F) by paediatricians during well-child care visits is feasible, valid and reliable. *Evidence-Based Medicine*, 22(4), 156. <https://doi.org/10.1136/ebmed-2016-110654>
- Durkin, M. S., Maenner, M. J., Baio, J., Christensen, D., Daniels, J., Fitzgerald, R., ... Yeargin-Allsopp, M. (2017). Autism spectrum disorder among US children (2002–2010): Socioeconomic, racial, and ethnic disparities. *American Journal of Public Health*, 107(11), 1818–1826. <https://doi.org/10.2105/AJPH.2017.304032>
- Durkin, M. S., Maenner, M. J., Meaney, F. J., Levy, S. E., DiGiuseppi, C., Nicholas, J. S., ... Schieve, L. A. (2010). Socioeconomic inequality in the prevalence of autism spectrum disorder: evidence from a US cross-sectional study. *PLoS One*, 5(7), e11551.
- Elsabbagh, M., Divan, G., Koh, Y. J., Kim, Y. S., Kauchali, S., Marcin, C., ... Fombonne, E. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism Research*, 5(3), 160–179. <https://doi.org/10.1002/aur.239>
- Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental disorders: An update. *Journal of Autism and Developmental Disorders*, 33(4), 365–382.
- Gabis, L., & Raz, R. (2010). The knowledge base of Israeli pediatricians in the area of child development. *Harefuah*, 149(1), 14–17.
- Guthrie, W., Wallis, K., Bennett, A., Brooks, E., Dudley, J., Gerdes, M., ... Miller, J. S. (2019). Accuracy of autism screening in a large pediatric network. *Pediatrics*, 144(4), e20183963. <https://doi.org/10.1542/peds.2018-3963>
- Kelly, B., Williams, S., Collins, S., Mushtaq, F., Mon-Williams, M., Wright, B., ... Wright, J. (2017). The association between socioeconomic status and autism diagnosis in the United Kingdom for children aged 5–8years of age: Findings

- from the Born in Bradford cohort. *Autism*, 23(1), 131–140. <https://doi.org/10.1177/1362361317733182>
- Kerub, O., Haas, E., Menashe, I., Davidovitch, N., & Meiri, G. (2018). Autism spectrum disorder: Evolution of disorder definition, risk factors and demographic characteristics in Israel. *Israel Medical Association Journal*, 20(9), 576–581.
- Kerub, O., Haas, E. J., Meiri, G., Davidovitch, N., & Menashe, I. (2018). A comparison between two screening approaches for ASD among toddlers in Israel. *Journal of Autism and Developmental Disorders*, 50, 1553–1560. <https://doi.org/10.1007/s10803-018-3711-x>
- Khowaja, M. K., Hazzard, A. P., & Robins, D. L. (2015). Sociodemographic barriers to early detection of autism: Screening and evaluation using the M-CHAT, M-CHAT-R, and follow-up. *Journal of Autism and Developmental Disorders*, 45(6), 1797–1808.
- Kogan, M. D., Vladutiu, C. J., Schieve, L. A., Ghandour, R. M., Blumberg, S. J., Zablotsky, B., ... Harwood, R. L. (2018). The prevalence of parent-reported autism spectrum disorder among US children. *Pediatrics*, 142(6), e20174161.
- Kuehn, B. M. (2012). Data on autism prevalence, trajectories illuminate socioeconomic disparities. *JAMA*, 307(20), 2137–2138. <https://doi.org/10.1001/jama.2012.3916>
- Leonard, H., Dixon, G., Whitehouse, A. J. O., Bourke, J., Aiberti, K., Nassar, N., ... Glasson, E. J. (2010). Unpacking the complex nature of the autism epidemic. *Research in Autism Spectrum Disorders*, 4(4), 548–554.
- Levaot, Y., Meiri, G., Dinstejn, I., Menashe, I., & Shoham-Vardi, I. (2019). Autism prevalence and severity in Bedouin-Arab and Jewish communities in Southern Israel. *Community Mental Health Journal*, 55(1), 156–160. <https://doi.org/10.1007/s10597-018-0236-x>
- Liptak, G. S., Benzon, L. B., Mruzek, D. W., Nolan, K. W., Thingvoll, M. A., Wade, C. M., & Fryer, G. E. (2008). Disparities in diagnosis and access to health services for children with autism: data from the National Survey of Children's Health. *Journal of Developmental and Behavioral Pediatrics*, 29(3), 152–160. <https://doi.org/10.1097/DBP.0b013e318165c7a0>
- Lord, C., Risi, S., Lambrecht, L., Cook, E. H., Jr., Leventhal, B. L., DiLavore, P. C., ... Rutter, M. (2000). The autism diagnostic observation schedule-generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, 30(3), 205–223.
- Maenner, M. J., Arneson, C. L., & Durkin, M. S. (2009). Socioeconomic disparity in the prevalence of autism spectrum disorder in Wisconsin. *Wisconsin Medical Journal*, 108(5), 37–39.
- Mahajnah, M., Sharkia, R., Shalabe, H., Terkel-Dawer, R., Akawi, A., & Zelnik, N. (2015). Clinical characteristics of autism spectrum disorder in Israel: Impact of ethnic and social diversities. *BioMed Research International*, 2015, 962093. <https://doi.org/10.1155/2015/962093>
- Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGiuseppi, C., Durkin, M. S., ... Kirby, R. S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, 99(3), 493–498. <https://doi.org/10.2105/ajph.2007.131243>
- Manor-Binyamini, I., & Shoshana, A. (2018). Listening to Bedouin mothers of children with autism. *Culture, Medicine and Psychiatry*, 42(2), 401–418. <https://doi.org/10.1007/s11013-018-9567-x>
- Matson, J. L., Worley, J. A., Fodstad, J. C., Chung, K.-M., Suh, D., Jhin, H. K., ... Furniss, F. (2011). A multinational study examining the cross cultural differences in reported symptoms of autism spectrum disorders: Israel, South Korea, the United Kingdom, and the United States of America. *Research in Autism Spectrum Disorders*, 5(4), 1598–1604.
- Meiri, G., Dinstejn, I., Michaelowski, A., Flusser, H., Ilan, M., Faroy, M., ... Menashe, I. (2017). Brief report: The Negev Hospital-University-Based (HUB) autism database. *Journal of Autism and Developmental Disorders*, 47(9), 2918–2926. <https://doi.org/10.1007/s10803-017-3207-0>
- Ministry of Health, Southern Health District, and Israel Center for Disease Control. (2008). The health status of Bedouin babies and children up to 6 years old in recognized localities and unrecognized localities.
- Raz, R., Weisskopf, M. G., Davidovitch, M., Pinto, O., & Levine, H. (2015). Differences in autism spectrum disorders incidence by sub-populations in Israel 1992-2009: A total population study. *Journal of Autism and Developmental Disorders*, 45(4), 1062–1069. <https://doi.org/10.1007/s10803-014-2262-z>
- Rea, K. E., Armstrong-Brine, M., Ramirez, L., & Stancin, T. (2019). Ethnic disparities in autism spectrum disorder screening and referral: Implications for pediatric practice. *Journal of Developmental and Behavioral Pediatrics*, 40(7), 493–500. <https://doi.org/10.1097/dbp.0000000000000691>
- Robins, D. L., Fein, D., Barton, M. L., & Green, J. A. (2001). The Modified Checklist for Autism in Toddlers: An initial study investigating the early detection of autism and pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 31(2), 131–144.
- Segev, A., Weisskopf, M. G., Levine, H., Pinto, O., & Raz, R. (2019). Incidence time trends and socioeconomic factors in the observed incidence of autism spectrum disorder in Israel: A nationwide nested case-control study. *Autism Research*, 12(12), 1870–1879. <https://doi.org/10.1002/aur.2185>
- Southern, J., Roizin, H., Daana, M., Rubin, C., Hasleton, S., Cohen, A., ... Regev-Yochay, G. (2015). Varied utilisation of health provision by Arab and Jewish residents in Israel. *International Journal for Equity in Health*, 14, 63. <https://doi.org/10.1186/s12939-015-0193-8>
- Tek, S., & Landa, R. J. (2012). Differences in autism symptoms between minority and non-minority toddlers. *Journal of Autism and Developmental Disorders*, 42(9), 1967–1973.
- The Central Bureau of Statistics of Israel. (2018a). Households and families. Statistical abstract of Israel.
- The Central Bureau of Statistics of Israel. (2018b). Live birth statistics. Statistical abstract of Israel.
- The Central Bureau of Statistics of Israel. (2018c). Total population. Statistical abstract of Israel.
- Treffert, D. A. (1970). Epidemiology of infantile autism. *Archives of General Psychiatry*, 22(5), 431–438. <https://doi.org/10.1001/archpsyc.1970.01740290047006>
- Wechsler, D. (1991). *Wechsler intelligence scale for children—Third Edition*. San Antonio, TX: The Psychological Corporation.



Retrieved from <https://www.pearsonassessments.com/HAIWEB/Cultures/en-us/Productdetail.htm?Pid=015-8979-044&Mode=resource%5Cnwww.pearsonclinical.com/psychology/products/100000310/wechsler-intelligence-scalefor-children-fourth-edition-wisciv.html?Pid=015-8979-044&>.

- Wiggins, L. D., Durkin, M., Esler, A., Lee, L. C., Zahorodny, W., Rice, C., ... Baio, J. (2019). Disparities in documented diagnoses of autism spectrum disorder based on demographic, individual, and service factors. *Autism Research, 13*, 464–473. <https://doi.org/10.1002/aur.2255>
- Zablotsky, B., Black, L. I., Maenner, M. J., Schieve, L. A., & Blumberg, S. J. (2015). Estimated prevalence of autism and other developmental disabilities following questionnaire changes in the 2014 National Health Interview Survey. *National health statistics reports, 87*, 1–20.
- Zablotsky, B., Black, L. I., Maenner, M. J., Schieve, L. A., Danielson, M. L., Bitsko, R. H., ... Boyle, C. A. (2019). Prevalence and trends of developmental disabilities among children in the United States: 2009-2017. *Pediatrics, 144*(4), e20190811. <https://doi.org/10.1542/peds.2019-0811>
- Zuckerman, K. E., Lindly, O. J., Reyes, N. M., Chavez, A. E., Macias, K., Smith, K. N., & Reynolds, A. (2017). Disparities in diagnosis and treatment of autism in Latino and non-Latino

White families. *Pediatrics, 139*(5), e20163010. <https://doi.org/10.1542/peds.2016-3010>

## Supporting Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

**Figure S1.** Kaplan–Meier plots for critical follow-up periods in the study. Kaplan–Meier plots display the time-dependent probabilities of diagnosis completion for the full follow-up time of the study (from M-CHAT screening until diagnosis completion; **A–C**), as well as for the referral period (from M-CHAT screening until first visit at the hospital; **D–F**) and for the diagnosis period (from first visit at the hospital until diagnosis completion; **G–I**). We compared these processes between Jewish (continuous line) and Bedouin (dotted line) toddlers for all toddlers in the study (**A,D,G**) and separately for toddlers with ASD (**B,E,H**) and without ASD (**C,F,I**).

**Table S1.** Cox Regression Models.