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Sociodemographic barriers to early detection of autism: screening and evaluation using the M-CHAT, M-CHAT-R, and Follow-Up

Meena K. Khowaja, M.A.,

Department of Psychology, Georgia State University, P.O. Box 5010, Atlanta, GA 30302-5010

Ann P. Hazzard, Ph.D., ABPP, and

Department of Pediatrics, Emory University School of Medicine, 49 Jesse Hill Jr. Drive, Atlanta, GA 30303

Diana L. Robins, Ph.D.

AJ Drexel Autism Institute, Drexel University, 3141 Chestnut St., Philadelphia, PA 19104

Abstract

Parents ($n = 11,845$) completed the Modified Checklist for Autism in Toddlers (or its latest revision) at pediatric visits. Using sociodemographic predictors of maternal education and race, binary logistic regressions were utilized to examine differences in autism screening, diagnostic evaluation participation rates and outcomes, and reasons for non-participation. Families of lower maternal education and racial minorities exhibited inflated initial screen positive rates and lower participation at Follow-Up, although not at evaluation. Economic challenges, such as invalid phone numbers, were identified as barriers to reaching these families. Families of higher education and White race were more likely to decline participation in evaluation. Results suggest the need for increased public education about childhood development to enhance awareness, reduce stigma, and streamline screening.

Keywords

screening; disparities; socioeconomic status; maternal education; race; autism

National surveillance data from the Centers for Disease Control and Prevention estimates the prevalence of autism spectrum disorder (ASD) as 1 in 68 children (Centers for Disease Control and Prevention 2014). The American Academy of Pediatrics (AAP) has recognized

Corresponding author: Meena Khowaja, Mkhawaja1@student.gsu.edu, Phone: (404) 413-6472, Fax: (404) 413-6589. Meena Khowaja, Department of Psychology, Georgia State University. Diana L. Robins, Department of Psychology, Georgia State University. Ann. P. Hazzard, Department of Pediatrics, Emory University School of Medicine. Diana L. Robins is now at AJ Drexel Autism Institute Drexel University.

¹The original M-CHAT and the revised M-CHAT-R are referred to together as M-CHAT(-R) throughout this article.

Regarding conflicts of interest, Diana Robins is co-owner of M-CHAT LLC, which licenses use of the M-CHAT in electronic products. However, data used in the current study were collected using the free version of the M-CHAT and no royalties are associated with this study. We certify that there is no conflict of interest, including financial interests, activities, relationships, and affiliations, with the authors and any organization or sponsor regarding the study design, data collection and analysis, writing of this manuscript, or the decision to submit the manuscript for publication.

the critical role of pediatricians in identifying children at risk for ASD and recommends autism-specific screening at 18- and 24-month well child visits, as well as routine ASD surveillance and broadband screening for other developmental disorders (Johnson et al. 2007).

The most extensively-studied measure currently used for population-based ASD screening is the Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al. 2001; Robins and Dumont-Mathieu 2006; Robins 2008). Parents complete the written M-CHAT questionnaire and at-risk responses are clarified using the Follow-Up protocol. The M-CHAT and Follow-Up has a positive predictive value (PPV) for ASD of .54 to .65 (Robins 2008; Kleinman et al. 2008; Chlebowski et al. 2013). Furthermore, only 19% of the children with ASD had been flagged by their pediatricians, supporting the notion that universal screening will enhance pediatricians' early detection efforts (Robins 2008). Recently, Robins and colleagues developed a revised version of the screener (M-CHAT-R; Robins et al. 2009; Robins et al. 2014), which simplified wording, added examples, and modified item order to discourage a positive response set; validation studies are ongoing with the M-CHAT-R.

Ascertaining whether the M-CHAT(-R)¹ is effective in screening for ASD across families of varying sociodemographic backgrounds is critical, given increasing concerns about health disparities according to family socioeconomic status (SES). Across a range of medical, developmental, and behavioral problems, individuals with lower SES (e.g., low income, less education, racial/ethnic minorities) have been found to have reduced access to healthcare and poorer quality of care, and it does not seem to be improving (Kuo et al. 2012; Strickland et al. 2009; Agency for Healthcare Research and Quality 2011). Furthermore, children with ASD in particular have also been found to have similar problems with access to medical homes and specialty care (Kohan et al. 2008; Tregnago and Cheak-Zamora 2012), and children with ASD from racial minority or low SES backgrounds were unlikely to experience rapid gains in social and communication skills (Fountain et al. 2012). Thus, low-SES families of children with ASD are at particular risk for receiving inadequate healthcare, which appears to negatively impact identification, access to intervention, and prognosis (Liptak et al. 2008).

Another factor that leads to poorer health outcomes, reduced access to and utilization of healthcare services, poorer self-management of medical conditions (e.g., asthma, diabetes), and higher risk of mortality, is low functional or health literacy (Baker et al 1997; Kaichman & Rompa 2000; Williams et al. 1998a; Mancuso & Rincon 2006; Williams et al. 1998b; Schillinger et al. 2002; Bostock & Steptoe 2012). Health literacy has been defined as a set of skills used to utilize healthcare services to help make informed decisions about one's health that promote better quality of life (Zarcadoolas et al. 2005), which also includes basic literacy for healthcare-related reading materials. Low health literacy is disproportionately higher in racial and ethnic minority groups (National Center for Education Statistics 2006).

Maternal education is frequently used as a marker variable for SES, although Shavers (2007) argues that the relationship between these variables is complex and may vary between racial/ethnic groups. In the current study, we examine the sociodemographic variables of maternal education and race, as these are related to one's socioeconomic status. The literature

suggests that most studies have not found ASD prevalence differences among families of varying social class and racial backgrounds (Fombonne 2003). Authors of studies which have found higher rates of ASD with increasing income (Durkin et al. 2010; Bhasin and Schendel 2007; Palmer et al. 2005) and maternal education (Bilder 2009) note that these prevalence differences may be due to disparities in identification of ASD (ascertainment bias), rather than actual differences in ASD rates. In addition, children of less educated mothers (Shattuck et al. 2009) and lower income families were older when they received ASD diagnoses (Mandell et al. 2005; Goin-Kochel et al. 2006), in part from increased likelihood of low-income families not attending evaluation appointments (Kalb et al. 2012). Moreover, racial disparities have been identified regarding age and accuracy of diagnosis of ASD. For example, Black children have been more likely to be diagnosed with ASD at a later age, and have been more likely to be misdiagnosed with other disorders (Mandell et al. 2002; Mandell et al. 2007)

Given the influence of early identification and treatment of ASD on prognosis, it is important to examine if and how sociodemographic factors (i.e., maternal education and race) might affect the screening process in a large, racially diverse sample. We hypothesized that parents with fewer years of formal education and of minority racial backgrounds are more likely to initially screen positive (i.e., at risk for ASD) on the M-CHAT(-R) than those with more education or of the majority race (i.e., White), given the literature regarding healthcare-related barriers. We hypothesized that White families and those with more education will show greatest consistency of screening results at Follow-Up, as more erroneous initial false positives would be identified in families with less education or racial minorities, but no difference in ASD rate by these sociodemographic variables. In assessing SES-related barriers to participation in multi-step ASD screening, we hypothesized that families with less education or racial minority status would be more likely not to participate in Follow-Up or evaluation.

Method

Participants

Participants were extracted from a larger ongoing project aimed at improving the sensitivity and specificity of the M-CHAT(-R) for detecting toddlers at risk for ASD. The larger screening study for the M-CHAT(-R) is a multi-site project taking place at two universities located in the northeastern and southeastern regions of the United States.. The current sample consists of only those from the southeastern site and includes both original and revised versions of the screening measure. As such, this sample partially overlaps with recent published data (Robins et al. 2014; Chlebowski et al. 2013), although with distinct research questions. This study involving human subjects was approved by the appropriate IRB ethics committee and was therefore performed in accordance with the ethical standards established in the 1964 Declaration of Helsinki and its later amendments. Inclusion criteria required parental informed consent, a child's age of 16 to 30 months at screening, motor and sensory ability to complete the evaluation, English-speaking parents, and available demographic data (i.e., maternal education, race/ethnicity). The sample consists of 11,845 participants whose parents completed either the M-CHAT ($n = 5,035$) or M-CHAT-R ($n =$

6,810) at a well-child pediatric appointment; mean age 20.8 months ($SD = 3.2$), 51.3% male (see Table 1). Maternal education ranged from less than 8th grade to graduate-level education (33% in the median with bachelor's degree). Sixty percent of the children were White, 26% were Black, and 14% were of other racial/ethnic minority backgrounds.

Measures

Screening—The Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al. 1999a) and the more recent Modified Checklist for Autism in Toddlers – Revised (M-CHAT-R; Robins et al. 2009), along with their corresponding Follow-Up questions administered in interview format, identified children at risk for ASD. The M-CHAT is a 23-item yes/no questionnaire on typical development and atypical behaviors commonly observed in ASD. Built-in Microsoft Word readability statistics software were used to examine Flesch-Kincaid grade level equivalents to indicate years of education needed to adequately understand text, as well as Flesch reading ease score (Flesch 1948; Kincaid et al. 1975). The reading ease score is based on a 100-point scale, with higher scores indicating greater ease; scores from 60 to 70 indicate understanding by most 13- to 15-year-old students, and scores of 90–100 are understood by most 11-year-olds. The M-CHAT has a 4.5 Flesch-Kincaid grade level and Flesch reading ease is 83.5. Internal consistency was reported to be adequate (Cronbach's $\alpha = .85$). Although true sensitivity, specificity, and negative predictive value (NPV) cannot be calculated without follow-up evaluations of children who showed no concerns on the M-CHAT, the sensitivity and specificity were estimated (using Discriminant Function Analysis) to be .97 and .95, respectively; the positive predictive value (PPV) and NPV were estimated to be .36 and .99, respectively. The PPV is improved when the Follow-Up was administered via a 5- to 20-minute parental interview to clarify at-risk item responses (Robins et al. 1999b 2009). The M-CHAT and Follow-Up has a positive predictive value (PPV) for ASD of .54 to .65, and a PPV for all developmental delays that warrant intervention of .90 to .98 (Robins 2008; Kleinman et al. 2008; Chlebowski et al. 2013). Kleinman and colleagues (2008) estimated an upper bound of sensitivity to be .91 based on a partial sample rescreened at age four.

The revised version, M-CHAT-R, is slightly shorter in length, consisting of 20 questions. Modifications from the original version included eliminating three items that demonstrated poor performance and rearranging item order to reduce affirmative response bias. To improve comprehension, wording was simplified and examples of each item were provided. Flesch-Kincaid readability statistics remained consistent with a 4.4 grade level and 86.3 reading ease. PPV, NPV, sensitivity, and specificity were estimated to be .48, .99, .85, and .99, respectively (Robins et al. 2014). In comparing the two versions, the inflated initial screen positive rate based on the questionnaire alone was significantly reduced (i.e., 9.15% vs. 7.17%) and ASD detection rate improved (i.e., 67 cases per 10,000 vs. 45 cases per 10,000). Although the PPV for questionnaire and follow-up interview was commensurate across versions, there was a significant improvement in ASD detection.

Evaluation—Families who screened positive on the M-CHAT(-R) questionnaire and subsequent interview were offered a free evaluation. Diagnostic evaluations were conducted by teams consisting of a licensed psychologist, graduate student, and research staff.

Measures included: Mullen Scales of Early Learning (Mullen 1995), Vineland Adaptive Behavior Scales, Second Edition (Sparrow et al. 2005), Behavioral Assessment System for Children, Second Edition (Reynolds and Kamphaus 2004), Autism Diagnostic Interview, Revised (Lord et al. 1994) or Toddler ASD Symptom Interview (Barton et al. 2012), Autism Diagnostic Observation Schedule (Lord 1999), Childhood Autism Rating Scale, First and Second Editions (Schopler et al. 1980; Schopler et al. 2010), and parent report of developmental history. Clinical judgment using all data and DSM-IV-TR criteria classified children as ASD or non-ASD.

Procedure

Pediatricians in a southeastern city were recruited to participate in a large autism screening study. Physicians invited parents attending 18-month and 24-month well-child visits to participate in a research study on child development. Consent and demographic information were obtained before parents read and completed the paper-and-pencil questionnaire. M-CHAT(-R) screens were scored by research staff at a public university in the southeastern United States, who called families with at-risk results ($n = 991$) to complete the Follow-Up. Those who continued to screen positive were invited to participate in a free diagnostic evaluation at the university ($n = 225$); see Figure 1. However, not all eligible families completed the interview ($n = 204$) or evaluation ($n = 75$). Parents received oral and written feedback that included test results, diagnosis, and recommendations.

Data Analysis

Two sociodemographic variables were measured: maternal education and race. Self-report of highest level of maternal education obtained was coded into four categories: 1) high school or less, 2) associate's degree/trade school/some college, 3) bachelor's degree, and 4) graduate degree. For analyses at the evaluation stage, maternal education was collapsed into two categories (i.e., some college or less vs. bachelor's degree or more) due to smaller sample sizes. Race was coded into two categories – minority racial ethnic groups (e.g., Black, Asian, Hispanic/Latino, multiracial, etc.) and White (not Hispanic/Latino). Binary logistic regressions were performed to ascertain the main effects (first block) of and interaction (second block) between maternal education and race on ASD screening and diagnostic outcome, as well as whether these predictors differentially related to participation rates and reasons for non-participation.

Results

Screening & Diagnostic Outcome

Main effects model for both maternal education and race was significant for predicting M-CHAT(-R) screening results, $\chi^2(4) = 249.6, p < .001$. Regression coefficients indicated that those with the lowest level of maternal education have 2.25 (95% confidence interval (CI) [1.83, 2.77]) times the odds as the highest education group of demonstrating risk at initial screening. Also, those who were racial minorities had higher odds of screening positive than White participants, odds ratio (OR) = 1.84, 95% CI [1.60, 2.13]. The interaction effect was not significant. See Table 2 for a summary of screening and diagnostic outcome based on sociodemographic factors.

Among those who completed the Follow-Up, a significant main effect for maternal education was found, $\chi^2(3) = 16.1, p = .001$, indicating that compared to the highest maternal education group, families of lower maternal education levels were less likely to continue to screen positive on the Follow-Up. This suggests that those with the highest level of education showed greatest consistency across questionnaire and interview. Race was not a significant predictor of outcome on the Follow-Up ($p = .442$). The interaction effect was not significant, Wald $\chi^2(3) = 7.10, p = .069$, although contrast comparisons suggested that Follow-Up outcome significantly varied by racial group (i.e., minorities were less likely to continue to screen positive than White individuals), but only within the lowest education group, Wald's $\chi^2(1) = 7.00, p = .008, b = -1.37, SE = .516, OR = .255, 95\% CI [.093-.702]$. Finally, at evaluation, neither the main effects model, $\chi^2(4) = 7.55, p = .110$, nor the interaction effects model, $\chi^2(3) = 1.29, p = .732$, for maternal education and race were predictive of diagnostic outcome.

Accuracy of the M-CHAT(-R) screen results in predicting ASD diagnosis (i.e., PPV) was examined across sociodemographic variables using chi square analyses. PPV is calculated as the proportion of children who screened positive and also received an ASD diagnosis (i.e., true positives) to all cases who screened positive on the M-CHAT(-R) regardless of diagnosis (i.e., true positives + false positives). PPVs for screening positive on the M-CHAT(-R) and Follow-Up were compared across maternal education levels and no significant differences were found, $\chi^2(1) = 4.85, p = .183, = .103$. PPVs were also similar across racial groups, $\chi^2(1) = 1.39, p = .238, = .238$. Table 3 lists diagnostic outcome and PPVs across sociodemographic variables.

To examine whether revisions to the wording of the M-CHAT(-R) played a role in screen positive rates, a binary logistic regression analysis was conducted to predict initial screening outcome, using M-CHAT(-R) version, maternal education, and race as predictors. Results demonstrated that as noted above, both maternal education and race made a significant contribution to prediction, $ps < .001$. However, M-CHAT(-R) version was not a significant predictor, $\chi^2(1) = .173, p = .677, b = .029, SE = .070, OR = 1.03, 95\% CI [.898, 1.18]$.

Participation Rates & Reasons for Non-Participation

In evaluating sociodemographic factors contributing to non-participation in multistep ASD screening, the main effects model was significant, $\chi^2(4) = 39.8, p < .001$. It was found that families with the least education had fewer odds of completing the Follow-Up than families with the highest education, Wald's $\chi^2(1) = 14.4, p < .001, b = -1.16, SE = .305, OR = .315, 95\% CI [.173, .572]$. Similarly, racial minorities were less likely to complete the Follow-Up than White families, Wald's $\chi^2(1) = 5.66, p = .017, b = -.447, SE = .188, OR = .639, 95\% CI [.442, .924]$. To further understand the relationship between maternal education, race, and participation in ASD screening, the most common reasons for nonparticipation – invalid number vs. non-responsive – were also compared. The main effects model indicated that the odds of non-participation due to an invalid phone number was higher for families with lowest maternal education, Wald's $\chi^2(1) = 4.67, p = .030, b = 1.74, SE = .801, OR = 5.68, 95\% CI [1.18, 27.3]$, and racial minorities, Wald's $\chi^2(1) = 3.86, p = .049, b = .826, SE = .421, OR = 2.29, 95\% CI [1.02-5.21]$. There was no significant interaction effect of maternal

education and race. However, when comparing families who had valid contact information and were reachable, no significant sociodemographic-based differences were found in Follow-Up completion rates for maternal education ($p = .140$), race ($p = .231$), or their interaction ($p = .985$). Table 4 provides rates of participation and reasons for non-participation broken down by demographic variables.

Given the smaller sample size at the evaluation phase, maternal education was collapsed into two categories for the following analyses. Among those who screened positive on the two-stage M-CHAT(-R) and Follow-Up and were invited for a free diagnostic evaluation, compared to those with the highest level of maternal education, those with less education were less likely to complete an evaluation, Wald's $\chi^2(1) = 6.56, p = .010, b = -.787, SE = .457, OR = .455, 95\% CI [.250, .828]$. However, race was not a significant predictor for evaluation participation rates ($p = .478$), nor were there interaction effects ($p = .854$). In terms of reasons for non-participation, the two most common reasons (i.e., declining vs. non-responsiveness) were compared. Main effects revealed that families with less maternal education, Wald's $\chi^2(1) = 12.6, p < .001, b = 2.26, SE = .636, OR = 9.57, 95\% CI [2.75, 33.3]$, and families who were of minority racial background, Wald's $\chi^2(1) = 6.56, p = .018, b = 1.50, SE = .637, OR = 4.48, 95\% CI [1.29, 15.6]$ were more likely to be non-responsive (i.e., not attending the scheduled appointment, or not responding to scheduling calls) than families of higher education and families who were White. No significant interaction effects were found.

Discussion

In examining disparities in M-CHAT(-R) outcome, study results suggested that children of families with lower education and racial minorities are more likely to initially screen positive, when compared to families with higher maternal education levels and White families. However, on the Follow-Up, most of these cases screen negative. This suggests that the Follow-Up plays a critical role in reducing the inflated screen positive rate for these families. The M-CHAT(-R) is a brief assessment that relies on parental knowledge of child behaviors. As such, the high screen positive rate among families with low maternal education and minority racial background on the initial M-CHAT(-R) may be due to reduced awareness of early childhood development and behaviors. Previous research has documented the significant correlation of SES-related factors, including maternal education and race, with reduced knowledge of child development (Reich 2005; Tamis-LeMonda et al. 1998; Zepeda & Espinosa 1988). In line with this, results in the current study indicated that families of higher maternal education, who likely have increased awareness of child development, exhibit greater consistency in screening outcome across both stages of screening. In a well-educated sample, parent concerns regarding child development were significantly related to performance on broadband screening tests (Glascoe et al. 2007) and developmental assessments (Rogers et al. 1992). Still, even parents of varying maternal education levels have demonstrated accuracy in estimating their child's developmental level (Pulsifier et al. 1994). As such, it is important that early detection practice continues to encourage collaborative parent-professional relationships that combine the expertise of both the providers and the parents as informants, as well as continued efforts towards increased parental awareness and education about child development.

To address issues of item misinterpretation, the M-CHAT-R clarified wording of questions and provided examples of target behaviors to help increase accuracy in completing the questionnaire. However, initial screening results were similar regardless of M-CHAT(-R) version completed. This suggests the need for something beyond changes to the written measure in order to achieve better screening accuracy for parents with lower maternal education. For example, outreach efforts to socioeconomically disadvantaged communities to increase awareness of child development and early intervention may facilitate patient-provider communication about developmental concerns. Although neither health (functional) literacy nor concrete literacy skills (e.g., reading and writing ability) were specifically measured, given their relatedness to low SES, it is possible that low literacy levels impeded accurate completion of the paper-and-pencil measure. However, the M-CHAT(-R)'s readability statistics were at the 4th grade level and, although not a direct measure of literacy, only 14 of the 11,845 participants reported having less than an 8th grade level of education. Additionally, pediatric office staff were trained to inquire about any questions the participants may have had, although no data were gathered assessing fidelity to this procedure. At community clinics in socioeconomically disadvantaged areas where literacy challenges may be more common, reading questions aloud can help reduce the possible impact of low literacy. This administration method would likely also increase attention to response; however, given the short time span during busy well child visits, it may be difficult for many providers to implement this approach.

After the comprehensive evaluation, most children (84%) received a diagnosis of a developmental disorder (e.g., ASD, language disorder, etc.) warranting intervention. Additionally, there were no differences in rates of ASD based on maternal education level or racial group, and the detection rate of ASD (i.e., PPV) did not differ across sociodemographic variables, demonstrating the benefit of screening across diverse samples. This finding is consistent with literature suggesting that individuals across diverse backgrounds are uniformly affected by ASD, and that prevalence disparities are more likely artifacts of historical inequities in the ASD identification process (Fombonne 2003). However, the data trends (see Table 3) suggest higher PPV as maternal education increases; although the effect sizes are small, in a larger sample these differences may reach statistical significance. This warrants continued consideration of such sociodemographic family factors when examining the accuracy and effectiveness of screening methodology in future research.

Though the Follow-Up interview is effective in reducing the initially high screen positive rate, racial minorities and families of lower maternal education have lower completion rates on the Follow-Up. This was primarily the result of having an invalid phone number, in most cases due to the number having been disconnected. For families with economic challenges, difficulties making bill payments or having short-term phone plans that are intermittently out of service may be a possible barrier. For example, Uebelacker and colleagues (2012) investigated barriers to providing care for depression to Latinos in a community setting by conducting focus groups. Participants commented in particular about difficulties with telephone contact, including how phones were often disconnected or changed when they were having financial difficulties. Thus, unique barriers to following up with economically disadvantaged families may exacerbate disparities. This suggests that immediate in-office

Follow-Up could be essential, though limited time and staffing in the pediatric setting may be an obstacle. For families with valid phone numbers, no sociodemographic-related differences were found in terms of interview completion rates. Having one-on-one attention, even if over the telephone, may be helpful in facilitating screening completion.

The majority (67%) of families completed free diagnostic evaluations after a screen positive outcome on the Follow-Up, although families of highest maternal education and White race were significantly more likely to participate. For families who did not participate despite recommendations from research staff, the primary reason for non-participation among families of higher maternal education and White race was actively declining to schedule the evaluation, whereas families with lower maternal education and minority race were non-responsive to phone calls to schedule the evaluation, or failed to attend scheduled appointments. It is possible that some families with higher social status (e.g., higher maternal education, White race) may experience greater denial about their children potentially having developmental difficulties due to perceived social stigma. Another explanation is that highly educated parents may feel more empowered to decline. In contrast, families of lower levels of education or of minority backgrounds may experience more of a power differential when contacted by university research staff and be more likely to passively decline by avoiding responding to phone messages. A third possibility is that families from lower education or minority backgrounds are more overwhelmed with other life stressors and therefore less proactive in returning phone calls to schedule an appointment. Initially in the study, families were called back separately after the Follow-Up to schedule an appointment for evaluation. Now, evaluations are scheduled during the Follow-Up phone call to help reduce dropout at this stage of the study. Additionally, it is possible that lack of transportation among more disadvantaged families could be a direct barrier to attending appointments and may have led to non-responsiveness. However, when scheduling appointments research staff inquired about transportation and occasionally conducted in-home evaluations as needed. Also, either parking on campus or public transportation fares were paid for by the study, to reduce transportation burden on participants.

In the current study, the majority of families participated in screening and evaluation, with four-fifths of the at-risk families participating in the Follow-Up, and two-thirds of the referred families completing an evaluation. Future implementation studies will be needed to determine whether similar participation rates are seen in community-based settings. It is difficult to estimate the rates of participation when applied to the general clinical setting, where typically both questionnaire administration and Follow-up interview would occur. In the current study, two-step screening was split across the pediatrician's office and via telephone by university research staff. A large part of the follow-through with families may have been due to the concerted efforts of research staff to contact families to conduct follow-up screening and schedule evaluations, whereas such resources may not be available in general clinical settings. On the other hand, removing the Follow-Up from the primary care provider's office may increase the difficulty of reaching families, thereby reducing participation rates. As such, electronic screening that integrates the administration of M-CHAT-R with Follow-Up into one step during the pediatric visit is currently being evaluated to streamline the screening process.

Another factor to consider when estimating participation rates in community settings is the importance of integrating screening with referrals for those children who show risk for ASD. Developing partnerships between pediatric clinics who conduct screening and diagnostic assessment clinicians and early intervention providers may be helpful for parents of children being referred for ASD risk. For example, Roux et al. (2012) have identified that use of a care coordinator to administer screening, make referrals, and develop an action plan for healthcare has been very helpful in serving low-income families. A final factor to consider regarding the clinical implications of screening participation rates is the proportion of pediatricians who are actively screening for ASD and other developmental delays, as recommended by the American Academy of Pediatrics (Johnson et al. 2007). Although the estimates of pediatricians using screening tools in their practice has risen from 23% in 2002 to 57% in 2009, there is still significant room for improvement (Radecki et al. 2011; Sand et al. 2005). This is especially important, given that using pediatrician observation for referrals without developmental screening can result in missing approximately 67% of children requiring evaluation (Hix-Small et al. 2007).

Limitations

As sample size decreased for later steps in the screening/evaluation process, there was less representation across each sociodemographic group, and this may have led to insufficient power to detect effects, particularly interaction effects. This in turn may limit the interpretability of the findings. The representativeness of the maternal education data collected to other community settings is also important to take into consideration. In the current sample, 79% of the families endorsed having received education beyond high school, whereas in a prevalence study only approximately half (58%) of the mothers had greater than 12 years of education (United States Department of Health and Human Services, Centers for Disease Control and Prevention, & National Center of Health Statistics, Division of Vital Statistics 2013). It is possible that pediatricians who agreed to participate in our study were located in and/or served communities with higher education levels.

Another important factor to consider is the relation between the sociodemographic variables of race and maternal educational attainment used in the current study and socioeconomic status. Although these race and education variables are related to SES, they are not directly interchangeable terms. Level of maternal education is commonly used as an estimate for socioeconomic status in the health disparities literature; however, alternative variables (e.g. census tract data, income, occupation) might lead to a more robust measure. Additionally, race and SES are correlated but are independent predictors of health outcome (LaVeist 2005), as unique sociocultural and historical factors contribute to racial disparities (e.g., stigma, segregation). Also, the degree of confounding between racial disparities and education level appears to be decreasing (Oliver & Shapiro 1997).

Future Directions

Study results led to several recommendations to help improve universal screening for ASD. It is imperative that screening with the M-CHAT(-R) includes the Follow-Up (Chlebowski et al. 2013), given its important role in preventing potential over-referrals for costly

diagnostic evaluations with long waiting lists, particularly for low SES families. The Follow-Up clearly helps increase specificity and PPV.

Two potential barriers contributing to disparities in autism screening are economic challenges (e.g., short-term phone plans, disconnected phone numbers) and reduced awareness of childhood development. One approach to overcome the first barrier is to combine the M-CHAT-R and Follow-Up. Currently, our group is pilot testing an electronic administration which integrates Follow-Up prompts for at-risk responses on the M-CHAT-R, which should eliminate difficulties reaching low-income families by phone for the Follow-Up. Additionally, with electronic administration, pediatricians can be alerted immediately of screen positive outcomes and encourage families to attend the diagnostic evaluation. Moreover, there is an option for items to be heard via audio recording, which may help resolve issues with literacy to some degree.

To address the second barrier, community outreach efforts could enhance the validity of ASD screening in underrepresented populations. For example, the Centers for Disease Control & Prevention has implemented the *Learn the Signs. Act Early* (LTSAE) outreach program (Daniel et al. 2009), which aims to improve early identification of developmental disabilities. The program has been effective in increasing parents' awareness of abnormal child development, parents' tracking of developmental milestones, and professionals' perception of competence in monitoring development. The LTSAE initiative has also collaborated with Health Resources and Services Administration (HRSA) and Association of University Centers on Disabilities (AUCD) to fund research investigating optimal methods to distribute educational knowledge and materials (Division of Birth Defects, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention 2014). For example, the list of funding awardees includes Stoneman and colleagues at the University of Georgia to investigate parents with low literacy living in poverty with toddlers in terms of their knowledge of child development, barriers to help-seeking behavior, and usefulness of LTSAE materials. Also, Vaughn and colleagues received funding towards *Project Conectar*, which is dedicated to reducing disparities in the early identification of ASD and other delays through a cultural competence-embedded health communication model among Hispanic and other diverse communities in Miami, Florida. An additional outreach approach is the use of face-to-face patient navigators, such as the *promotores* model within the Latino community, as a means to reach out to communities who otherwise have limited access to and utilization of health services (Brown and Harris 1995; Corkery et al. 1997; Lorig et al. 2001). Navigators typically encourage families to actively utilize screening and evaluation services and empower them to voice questions rather than avoiding addressing concerns with providers.

In conclusion, to best reach families of diverse socioeconomic backgrounds, it will be important to engage in universal and efficient screening practices, avoiding middle steps that can result in dropout, such as the combined M-CHAT-R and Follow-Up electronic administration. Also, provision of patient education about child development in the clinic and community, encouragement of open provider-patient communication, and efforts to destigmatize developmental problems may result in higher rates of screening participation and more accurate parental reporting.

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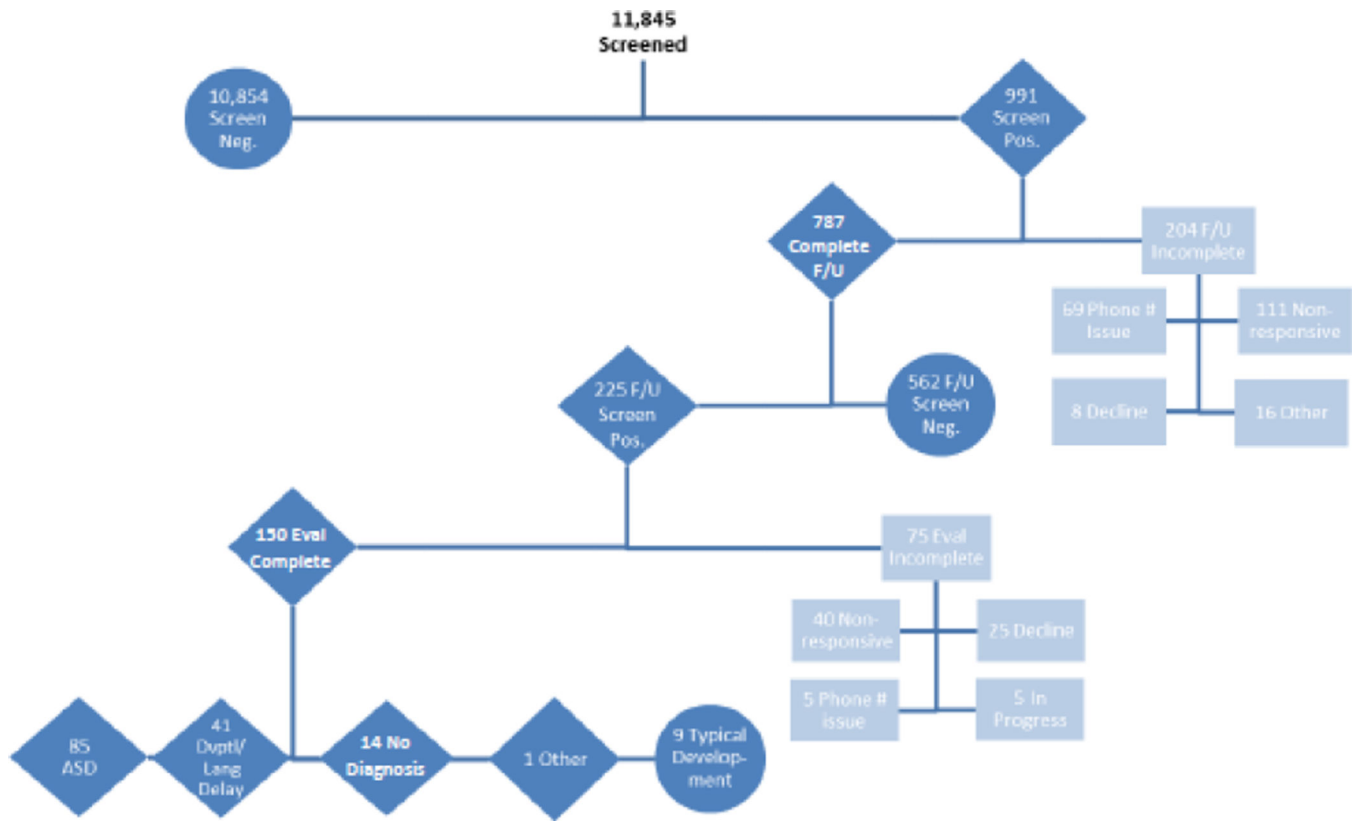


Figure 1. Flowchart of multistep ASD screening outcome
 Note. □ = incomplete participants, ○ = not at-risk/healthy, ◊ = at-risk. “Dev/Lang delay” includes children diagnosed with Global Developmental Delay, and receptive and/or expressive language disorders. “Other” includes one child diagnosed with Phonological Disorder.

Table 1
Demographic Data for Child's Age, Sex and Race/Ethnicity and Maternal Education

	M-CHAT(-R) Screening (n = 11,845)		Follow-Up Screening (n = 787)		Evaluation (n = 150)	
	Mean	SD	Mean	SD	Mean	SD
Age (months)	20.8	3.2	24.6	5.5	26.4	5.9
	n	%	n	%	n	%
Male	6,073	51.3	467	59.3	103	68.7
Female	5,772	48.7	320	40.7	47	31.3
White, NOT Hispanic/Latino	7,141	60.3	350	44.5	69	46.0
Black, NOT Hispanic/Latino	3,088	26.1	315	40.0	51	34.0
Asian, NOT Hispanic/Latino	396	3.3	30	3.8	6	4.0
White, Hispanic/Latino	199	1.7	23	2.9	6	4.0
Black, Hispanic/Latino	62	.5	6	.8	2	1.3
Asian, Hispanic/Latino	8	.1	0	.0	0	.0
Unknown, Hispanic/Latino	179	1.5	3	.4	1	.7
Multiracial or Other	772	6.5	60	7.6	15	10.0
< High School	516	4.4	78	9.9	11	7.3
High School/GED	1,937	16.4	178	22.6	21	14.0
Assoc/Trade/Some college	2,790	23.6	205	26.0	35	23.3
Bachelor's degree	3,948	33.3	191	24.3	39	26.0
Graduate degree	2,654	22.4	135	17.2	44	29.3

Table 2
 Screening Outcome and Diagnostic Outcomes across SES, n (% within race group by education level)

		High school/ GED or less	Some college	Bachelor degree	Graduate degree
<i>INITIAL M-CHAT(-R) SCREENING</i>					
Minority					
	Screen positive	305 (17.5)	135 (10.8)	86 (8.5)	58 (8.1)
	Screen negative	1437 (82.5)	1112 (89.2)	916 (91.5)	655 (91.9)
White					
	Screen positive	60 (8.4)	111 (7.2)	144 (4.9)	92 (4.7)
	Screen negative	651 (91.6)	1432 (92.8)	2802 (95.1)	1849 (95.3)
<i>FOLLOW-UP SCREENING</i>					
Minority					
	Screen positive	41 (19.4)	32 (29.6)	22 (32.4)	26 (52.0)
	Screen negative	170 (80.6)	76 (70.4)	46 (67.6)	24 (48.0)
White					
	Screen positive	14 (31.1)	26 (26.8)	35 (28.5)	29 (34.1)
	Screen negative	31 (68.9)	71 (73.2)	88 (71.5)	56 (65.9)
<i>EVALUATION OUTCOME</i>					
Minority					
	ASD	12 (48.0)	11 (55.0)	10 (66.7)	17 (81.0)
	Non-ASD	13 (52.0)	9 (45.0)	5 (33.3)	4 (19.0)
White					
	ASD	3 (42.9)	8 (53.3)	11 (45.8)	14 (60.9)
	Non-ASD	4 (57.1)	7 (46.7)	13 (54.2)	9 (39.1)

Table 3
 Diagnostic Outcome and PPV for Cases Who Completed Evaluation after Screening Positive on M-CHAT(-R) and Follow-Up

	ASD	Non-ASD	PPV	95% CI
<i>Overall</i>	86	64	.573	.494–.652
<i>Maternal education</i>				
High school or less	15	17	.469	.296–.642
Some college	19	16	.543	.378–.708
Bachelor degree	21	18	.538	.382–.695
Graduate degree	31	13	.705	.570–.839
<i>Race</i>				
Minority	50	31	.617	.511–.723
White	36	33	.522	.404–.640

Table 4
 Participation Rates and Reasons for Non-Participation, n (% within race group by education level)

FOLLOW-UP COMPLETION		High school/ GED or less	Some college	Bachelor degree	Graduate degree
Minority					
	Yes	211 (72.3)	108 (82.4)	68 (79.1)	50 (86.2)
No: non-responsive		38 (13.0)	15 (11.5)	12 (13.9)	6 (10.3)
No: phone # issue		43 (14.7)	8 (6.1)	6 (7.0)	2 (3.5)
White					
	Yes	45 (77.6)	97 (88.2)	123 (87.2)	85 (93.4)
No: non-responsive		6 (10.3)	12 (10.9)	16 (11.4)	6 (6.6)
No: phone # issue		7 (12.1)	1 (0.9)	2 (1.4)	0 (0.0)
EVALUATION COMPLETION		Some college or less	Bachelor degree or higher		
Minority					
	Yes	45 (65.2)	36 (80.0)		
No: non-responsive		1 (1.5)	6 (13.3)		
No: decline		23 (33.3)	3 (6.7)		
White					
	Yes	22 (56.4)	47 (75.8)		
No: non-responsive		10 (25.6)	4 (6.5)		
No: decline		7 (18.0)	11 (17.7)		