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Sociodemographic differences in parental satisfaction with an autism spectrum disorder diagnosis†

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Abstract

Background—The diagnostic process for autism spectrum disorder (ASD) can be difficult for families. Growing evidence suggests that the diagnostic process may vary as a function of sociodemographic factors, such as socioeconomic status. The purpose of this study was to extend findings related to families' experiences obtaining a diagnosis and accessing services for their young child with ASD.

Method—A mixed methods approach was used in this study, in which 46 families with children with ASD participated. A chi-square analysis compared ratings of parental satisfaction with the diagnostic process and current services between sociodemographic groups, and this was supplemented by thematic analysis of relevant open-ended questions.

Results—Results indicated that satisfaction ratings varied significantly by maternal education and family income levels. Ratings of satisfaction with the child's paediatrician also differed by family income. Major themes from the open-ended questions are discussed.

Conclusions—Results support assessing satisfaction and barriers in families seeking healthcare and school-based services to facilitate access to services.

Keywords

ASD; autism spectrum disorder; diagnosis; parent satisfaction; family income; maternal education

Introduction

Autism spectrum disorder (ASD) is the fastest growing neurodevelopmental disorder in childhood, affecting an estimated 1 in 68 children in the United States (US; Centers for Disease Control and Prevention, 2014) and comparable numbers in Europe and the Western Pacific (Elsabbagh et al., 2012). ASD is marked by deficits in social functioning and interaction, language and communication, and appropriate play skills (American Psychiatric Association, 2013).

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Early identification of ASD is essential for accessing services and determining a child's eligibility for school and community-based interventions. Providing intensive early intervention is critical to maximising outcomes for children with ASD, and evidence suggests that the earlier intervention can begin, the better the outcome (Woods & Wetherby, 2003). Previous findings suggest that there are diagnostic disparities in the US and elsewhere among children with ASD as a function of sociodemographic variables, such as race, ethnicity, and socioeconomic status (SES; Croen, Grether, & Selvin, 2002; Elsabbagh et al., 2012; Liptak et al., 2008; Mandell, Listerud, Levy, & Pinto-Martin, 2002). Furthermore, risk factors in the US, such as ethnic or racial minority status, living in poverty, and receiving health insurance based on poverty need are each associated with less access to services compared to groups without these identified risk factors (Liptak et al., 2008). These risk factors often co-occur such that ethnic or racial minority status may also be associated with poverty. Mandell et al. (2002) reported that Latino children in Philadelphia, a large metropolitan US city, were less likely than White children to have health insurance, three times as likely to live in households that fall below the poverty line, twice as likely to lack a regular source of medical care, and 1.3 times as likely to experience difficulty accessing specialty care. The existing literature highlights the overlap in groups at higher risk of ASD and groups facing more barriers to accessing services. Close examination of factors associated with diagnosis and access to services may yield findings important for professionals working with families and children with ASD, including how to better serve underrepresented groups.

Recent epidemiological studies suggest an increased risk for ASD among lower SES groups (e.g., Harris, 2012), yet individuals from higher SES backgrounds are more often identified than their lower income counterparts (Durkin et al., 2010). Durkin and colleagues interpreted these differences as an indication of an underrepresentation of children with ASD from low and middle SES backgrounds in the US and an overrepresentation of children in higher SES groups. They argued that parents with higher SES may be more likely to persist in finding a diagnosis to obtain services for their children, resulting in earlier diagnosis and higher prevalence rates. Another possible explanation is that this persistence in higher SES parents might result in an increase in the diagnosis of milder cases of ASD in order to obtain services, resulting in an overdiagnosis in higher SES groups (Durkin et al., 2010; Harris, 2012). Noting that only limited data were available for low-income countries, Elsabbagh et al. (2012) did not find evidence that SES, geographic region, or cultural differences contributed to differing prevalence rates worldwide.

SES differences in the US in ASD diagnoses extend beyond risk and prevalence rates. Mayes and Calhoun (2011) examined demographic predictor variables of ASD symptoms in a sample of 777 children aged 1–17 years in the Northeast US. The investigators found that ASD severity did not differ by race or gender; however, behaviour and mood problems were significantly more common in the lower SES group than the higher SES groups, controlling for gender and race. Specifically, in professional families, 86.8% of children had overreactivity, meltdowns, and/or aggression, in contrast to 94.2% in nonprofessional families. In professional families, 66.9% of children were described as moody or labile, in contrast to 81.0% in nonprofessional families. In this study, children from low SES families

had more severe ASD symptomatology than those from higher SES families, which could contribute to different experiences and levels of stress related to the diagnostic process.

Family characteristics can also influence types of services accessed and used. Irvin, McBee, Boyd, Hume, and Odom (2012) examined how child and family factors, namely, SES, caregiver race/ethnicity, and caregiver stress, are associated with service receipt for 137 preschool-aged children with ASD and their families in American schools and private settings. For those receiving school-based services, students with Hispanic caregivers received significantly less speech-language therapy (SLT) and occupational therapy (OT) than students with White caregivers. Students with Asian caregivers received significantly less OT than students with White care-givers. For those receiving private therapy services, higher SES was associated with higher probability of receiving OT compared to lower SES families. Lastly, higher SES was associated with a higher likelihood of receiving treatments based on the principles of applied behaviour analysis (ABA; Cooper, Heron, & Heward, 2007). Thus, in this study, family SES and race/ethnicity were associated with the type and dosage of services used. One limitation, however, is that White families were more likely to be in high SES groups than Hispanic and Black families, and there was no mention of controlling for this possible confound. Cooper et al. (2007) speculate higher SES families may be in a better position to advocate for their child to receive higher dosages and specific treatments, such as those based on the principles of ABA, than parents in the lower SES groups. If higher SES families are also White, differences in treatment type and dosage could also be due to cultural or ethnic/racial bias among service providers, leading to different family experiences during the diagnostic and service utilisation process.

Among US families with children with an ASD diagnosis, parents often report experiencing frustration and confusion throughout the diagnostic process (Ahern, 2000; Schall, 2000). Results of qualitative studies examining parents' experiences during the diagnostic process have suggested that some physicians tend to minimise or dismiss parents' concerns about their children. Despite the fact that child outcomes are most favourable when early intensive interventions are provided, these physicians often instruct parents to "wait and see," leaving parents feeling frustrated and resentful with the diagnostic process (Ahern, 2000; Schall, 2000). Among families with a child with ASD in Northern Ireland and the Republic of Ireland, parents reported an average of 12 and 14 months to complete the diagnostic process, respectively. Furthermore, most parents felt that at the time of diagnosis the advice from health providers was not sufficient for their child and family (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010). It is important to note, however, that several factors, including child symptom severity and family demographic variables, can influence parents' experiences, as well the appraisal of their experiences with the diagnostic process.

There is a dearth of studies examining family experiences receiving diagnostic evaluations and services, and even fewer studies that examine differences based on sociodemographic variables. One cross-sectional study of 494 families with children with ASD included families in six countries: the US, Ireland, England, Australia, New Zealand, and Canada (Goin-Kochel, Mackintosh, & Myers, 2006). Higher levels of parental education and income were associated with earlier diagnosis and greater satisfaction with the diagnostic process. Additionally, parents were more satisfied with the diagnostic process when they saw fewer

professionals and obtained a diagnosis for their child at a younger age. That is, the higher the parents' level of education, the greater their family income, and the younger that children were when they received an ASD diagnosis, the more satisfied parents were with the process of getting a diagnosis. Another study focused on parental satisfaction during the diagnostic process for 102 Singaporean families of children diagnosed with ASD (Moh & Magiati, 2012). The parents most satisfied with the diagnostic process perceived a higher level of collaboration with professionals, found the information that they received to be more helpful, were less stressed, and their child diagnosed with ASD had a lower severity of ASD symptoms.

Parents' beliefs and interpretations of the symptoms and etiology combined with their experiences with the healthcare system may influence treatment decisions. Parental satisfaction with the diagnostic process may set the stage for how parents proceed with treatment options for their child and develop relationships with professionals. Thus, assessing parental satisfaction may yield valuable information for improving the service delivery system for families of children with ASD. On a larger scale, findings may help professionals and policymakers to work toward supporting equitable diagnostic pathways for parents and children in underrepresented sociodemographic groups.

Purpose of the study

The purpose of the study was to extend findings related to US families' experiences with the diagnostic process for their child with ASD. In the first analysis, we examined how families' experiences varied by a set of SES indicator variables. Specifically, we sought to explore whether parental satisfaction with the diagnostic process and the child's current services varied as a function of maternal education, family income, and type of health insurance. In the second analysis, we examined open-ended questions regarding barriers to early identification and experiences with healthcare professionals, to shed light on common themes, challenges, and barriers within our sample.

Method

This study was part of a larger investigation examining child, family, and community variables associated with early identification and treatment of ASD in the Northwestern US. Child and family demographic data, family experiences surrounding accessing medical information and care, and service and treatment utilisation information were collected via in-home interviews with primary caregivers. Participating caregivers were informed about the study, signed consent forms, and understood that information provided would be kept confidential. This study was approved by the authors' Institutional Review Board at the University of Oregon.

To be eligible for the study, the child (a) was 7 years old or younger; (b) had a prior child diagnosis of autistic disorder, pervasive developmental disorder not otherwise specified, or Asperger syndrome; and (c) had lived with his or her primary caregiver for 1+ years. Recruitment of children and families occurred via early childhood programs, community clinics, and organisations. Interested caregivers responded to invitation letters and contacted the research office. Participants were screened by telephone for eligibility. A longer phone

call and a 2-hour at-home structured interview with some open-ended questions were conducted to collect information regarding the child's adaptive behaviour, ASD symptoms, temperament and atypical behaviour, family sociodemographic variables, and family experiences with obtaining a diagnosis and services for their child. These measures were self-reported by parents during the interview. Data from a subsample of 46 families with young children (aged 2–7 years) with ASD comprise the sample for the current study.

Participants

Of the 46 families included in the study, two-thirds of primary caregivers (n = 31) reported completing 12 years of schooling or less. Approximately one-quarter of families (n = 13) reported household incomes that fell at or below the US federal poverty line. Seventy percent of caregivers (n = 32) reported receiving Medicaid or health insurance through their state health plan (available for lower income families), whereas 30% reported having private insurance (n = 14). Three-quarters (n = 35) of primary caregivers identified as White/Caucasian, 13% identified as Latino/Hispanic (n = 6), 4% identified as Asian (n = 2), with the remaining 7% identifying as Black or Mixed race (n = 3). The racial/ethnic demographics are consistent with the geographic catchment area from which the data were drawn (United States Census Bureau, 2010). In all cases, respondents were mothers or other female caregivers. In eight interviews a male caregiver was also present.

Measures

Demographics—A questionnaire was developed for the present study that asked about child and family demographic variables. Sociodemographic variables of interest for the present study included maternal education, family income, and type of health insurance. Maternal education referred to the level of education the female primary caregiver in the household received. Family income included gross annual income for the household. Type of child health insurance was categorised as private insurance or state-funded health insurance plans for lower income families.

Parental satisfaction—Respondents were asked to self-report their level of satisfaction with their child's (a) special education eligibility assessment (school diagnostic process), (b) medical diagnostic evaluation, and (c) care from medical professional (i.e., paediatrician or primary care physician). Satisfaction was reported on a 5-point scale (1 = *very unsatisfied*, 3 = *neutral*, 5 = *very satisfied*).

Barriers to care—Respondents were asked four open-ended questions regarding barriers, concerns, and interactions with healthcare professionals during their child's diagnostic process. The first question asked caregivers to comment on their experiences with their child's paediatrician. The second question asked caregivers to describe their experiences with other healthcare and educational professionals. The third question asked caregivers to describe whether there were any barriers to earlier identification/diagnosis. The final question asked caregivers to provide any other information they wished to share. These items were part of the semistructured interview. Caregivers' responses were dictated and later coded using thematic analysis.

Data analysis

Dichotomous variables were created for education (0 = more than high school, 1 = high school diploma or less), income (0 = above federal poverty line, 1 = at/ below federal poverty line), and insurance (0 = private insurance, 1 = Medicaid or state health plan). The Likert-type items were condensed from 5 to 3 items and coded as 0 for *unsatisfied*, 1 for *neutral*, and 2 for *satisfied*. Chi-square analyses were run to test for significant differences in each satisfaction measure between groups. Chi-square analysis assumptions include independence of observations, unbiased sampling, and appropriate distribution of frequencies (Urdan, 2001). Based on examination of the distribution and descriptive data, all assumptions were tenable.

In addition to conducting chi-square analyses, we conducted a thematic analysis (Braun & Clarke, 2006) with the responses to open-ended questions. We transcribed the responses and coded information pertaining to common challenges, barriers, and themes that arose in these families' experiences of obtaining a diagnosis and accessing services. After careful examination, we grouped responses into two categories: challenges with the process in general and barriers to obtaining an earlier diagnosis. Challenges were then grouped into four subcategories that captured all the challenges mentioned by parents: (a) challenges with service delivery from a medical professional; (b) challenges with limited quantity or type of services available; (c) challenges with service delivery from education professionals; and (d) challenges with public transport.

Families also mentioned several barriers to obtaining an early diagnosis. In order to represent all the barriers mentioned by the families in our sample, seven categories were created: (a) paediatrician/ medical professional; (b) parent denial; (c) ineffective screening tools; (d) financial; (e) time; (f) cultural stigma; and (g) lack of public awareness. Each of these subcategories of challenges and barriers were coded in SPSS Version 21.0 (IBM Corp, 2012) as dichotomous categorical variables (11 total), with the two levels coded either 1 for "yes," mentioned by parent, or 0 for "no," not mentioned by parent. Many families mentioned several challenges or barriers; these variables were not mutually exclusive. We calculated frequencies and percentages for these variables and then ran bivariate point biserial correlations to examine any potential correlations between challenges, barriers, and SES.

Results

Results from the chi-square analyses indicated a significant difference in satisfaction ratings of the special education eligibility process (school diagnosis) by maternal education, $X^2(2, N = 43) = 6.46$, $p = .04$, as well by household income, $X^2(2, N = 43) = 8.17$, $p = .02$. Further, Cramér's effect size value (V = .39) and (V = .44), respectively, suggested a moderate practical significance. Specifically, care-givers with less education as well as caregivers with higher household incomes were more likely to report higher satisfaction with the school diagnosis process for their child. Insurance type did not have a significant relationship with satisfaction ratings of the school diagnosis process. Caregiver reports of satisfaction with care from their child's paediatrician significantly differed by household income, $X^2(2, N = 46) = 6.32$, $p = .04$, such that caregivers with higher household incomes were more likely to

report being satisfied with the care received from their child's paediatrician. Satisfaction with their child's paediatrician did not differ by insurance type or maternal education. Further, Cramér's effect size value (V = .37) suggested a moderate practical significance. Lastly, satisfaction ratings with current services and with the medical diagnostic process did not significantly differ by any of the examined sociodemographic factors.

Results from the thematic analysis indicated 78% of families (*n* = 36) reported to have faced challenges with service delivery from medical professionals, specifically with their child's paediatrician. The most common specific complaints regarding medical professionals were that paediatricians "don't listen to parents," and "didn't validate my concerns." Twenty percent of families (*n* = 9) specifically identified a challenge with limited services and/ or type of services available. Several parents noted that "there are too few services" offered and that there is a need for "at-home services" for parents with children with ASD. Fifteen percent of families (*n* = 7) identified challenges with service delivery from education professionals, with many parents referring specifically to a lack of training and awareness around children with ASD. Lastly, 4% of families (*n* = 2) indicated that public transport was a challenge to use with a child with ASD. One family elaborated that public transportation employees were "insensitive." Eleven percent of families (*n* = 5) did not mention any specific challenges.

With regard to barriers to receiving an earlier diagnosis, 54% of families (*n* = 25) expressed that the paediatrician or other medical professional was a barrier. In 20 of these 25 responses, parents specifically identified a paediatrician as a reason for waiting to get a diagnosis of ASD for their child. Again, many families elaborated that the paediatrician dismissed or invalidated their concerns. In one instance, the parents said they later found the doctor had written some concerns in their child's chart, but did not mention them to the parents until much later. Many families voiced a need for more open communication between parents and doctors, and for doctors to listen to parents' concerns. Of those reporting barriers, 20% of families (*n* = 9) said that financial constraints were a barrier. One of these families specifically mentioned that their health insurance was an issue. Thirteen percent of families (*n* = 6) identified their own denial as a barrier to earlier diagnosis, whereas 9% of families (*n* = 4) said that ineffective screening tools were a barrier, including that developmental screening tools were "too broad" or "cookie cutter" to catch the array of presenting ASD symptoms. Nine percent of families (*n* = 4) mentioned that a lack of public awareness was a barrier for them, including that they did not know what to look for or the kinds of questions to ask their doctor. Seven percent of families (*n* = 3) specifically mentioned stigma as a barrier to an earlier diagnosis, such that they did not want their child to be labelled "autistic." Lastly, 7% of families (*n* = 3) said lack of time was a barrier given the time needed to seek out medical and diagnostic evaluation appointments. Twenty-six percent of families (*n* = 12) said they did not experience any barriers. Only 7% percent of families (*n* = 3) did not mention any challenges or barriers to receiving a diagnosis for their child.

Table 1 depicts the results of point biserial correlations between the SES-indicator variables and the challenges and barriers variables. There was a significant negative correlation with a moderate effect size between family income and challenges regarding the quantity or type of

services available, such that families above the poverty line were more likely to mention too few services available than families at or below the poverty line, Pearson's $r(46) = -.31$, $p = .04$. There was also a significant negative correlation with a moderate to large effect size between mentioning financial constraints as a barrier and maternal education, such that mothers with more than a high school diploma were more likely to mention financial constraints as a barrier than mothers with a high school diploma or less, Pearson's $r(46) = -.48$, $p = .00$. Finally, there was a significant positive correlation with a moderate effect size between maternal education and reporting no barriers to early identification, such that mothers with a high school education or less were more likely to report no barriers to early identification, whereas mothers with more than a high school education were more likely to report at least one barrier, Pearson's $r(46) = .33$, $p = .02$.

Discussion

The purpose of this study was to examine sociodemographic disparities in family experiences obtaining and utilising services for their child with ASD. Specifically, we explored whether parental satisfaction ratings with the diagnostic process, education eligibility process (school diagnosis), and child's paediatrician varied as a function of family income, maternal education, and type of health insurance. We also conducted a thematic analysis with responses to open-ended questions regarding challenges and barriers to early diagnosis and access to services.

Results partially supported previous findings that parental satisfaction ratings varied as a function of sociodemographic variables. Differences in maternal education and household income, but not insurance type, were associated with differences in satisfaction with the special education eligibility process (school diagnosis) and with their child's paediatrician. Similar to previous findings (Goin-Kochel et al., 2006; Moh & Magiati, 2012), parents with higher household incomes were more likely to report being satisfied with the process of obtaining special education eligibility for their child than parents with lower incomes. In addition, families with higher incomes were also more likely to report being satisfied with the care their child was receiving from their paediatrician than were families with lower incomes. Families from higher SES groups may face fewer barriers to accessing services than families from lower SES groups. Furthermore, being in a higher SES group is associated with receiving more types of services, such as ABA-based treatment and OT, whereas being in lower SES groups is associated with receiving fewer types of services (Irvin et al., 2012). This could lead to a discrepancy in type and quality of service between groups, demonstrating that disparities in SES may manifest themselves as disparities in other domains. Conversely, existing literature supports a relation between low SES, elevated levels of chronic stress, and elevated levels of depression (Adler & Ostrove, 1999; Baum, Garofalo, & Yali, 1999). If parents with lower incomes report more stress and are more likely to face diagnostic and service barriers, then a lower quality experience in accessing care may play a role in increasing stress and depression levels. Indeed, in Singapore, Moh and Magiati (2012) found that parents of a child with ASD who consulted more professionals during the diagnostic process and who perceived lower levels of collaboration with professionals were more stressed.

Maternal education was also related to satisfaction ratings of the education eligibility process (school diagnosis). In this case, mothers with a high school level of education or less were more likely to report being satisfied than mothers with more than high school education. Mothers who are higher educated may be more informed about best practices for ASD diagnosis and intervention. According to the US National Research Council, programs serving young children with ASD should provide a minimum of 25 hours of intervention a week, 12 months out of the year (Downs & Downs, 2010). Only 13% of families in our sample were receiving this level of care. As such, it could be that families with higher maternal education were more likely to be aware of the discrepancy between the services they were receiving and the best practices recommendations. This could lead to dissatisfaction with different aspects of the diagnostic process, in this case, obtaining education eligibility. Still, we do not have specific qualitative information from families describing why they may have been more or less satisfied.

From the open-ended questions, we do have information on specific challenges faced during the diagnostic process and barriers to early identification as mentioned by families. Four categories of challenges were reported: challenges with service delivery from medical professionals, challenges with the limited quantity or type of services available, challenges with service delivery from education professionals, and challenges with public transportation. Leiter and Krauss (2004) found similar themes among parents with children with special needs. Findings from Leiter and Krauss suggest that for parents requesting additional school-based services for their child, approximately 20% reported each of the following problems: the available services were inadequate, the service was not available, the parents had trouble finding the right kind of service, or the school would not help the parents find the services. Approximately half of the parents who requested additional services reported other, albeit unspecified, problems in obtaining them. In the current study, families also mentioned several barriers to obtaining an early diagnosis, including a paediatrician/medical professional, parent denial, ineffective screening tools, financial constraints, time constraints, stigma, and general lack of public awareness.

Significant relations emerged between maternal education and reports of financial constraints as a barrier, as well as between maternal education and reporting no barriers whatsoever. We postulate that mothers with more education may be less satisfied and more aware of challenges and barriers because they are more aware of best practices in general. There was also a significant relation between family income and reporting challenges with services available. Higher income families were more likely to report inadequate services available than families with lower incomes. Indeed, higher income families were more likely to report wanting more and different types of services for their child.

Limitations

Despite the fact that the sociodemographic characteristics in our sample are consistent with the geographic catchment area from which the data were drawn, the sample was relatively small, which may limit generalisability. A self-reported satisfaction rating scale was used in this study. Some researchers view the concept of “satisfaction” as relative. Fitzpatrick (1997), for example, suggested that satisfaction reflects the difference between the quality of

care expected relative to what is received. It is possible that other factors, such as obtaining a medical diagnosis and school diagnosis, regardless of how satisfactory the process was, might have more profoundly influenced parents' perceptions of the experience. According to research on memory and recall, emotional states at the time of both encoding and recall can influence how events are recalled (Dehon, Lerøi, & Van der Linden, 2010). That is to say, parents may be so relieved or content with obtaining a diagnosis and services for their child that their emotional state at the time of the interview may not align with how they felt at the time of diagnosis. This incongruence may shift their appraisal of their experiences. Lastly, the method of recruiting families through ASD community organisations may have introduced some systematic bias (e.g., toward families using available services), thereby suggesting that results may not generalise to the experiences or beliefs of families who are not affiliated with such organisations. With regard to our analysis, thematic analysis in particular has limited interpretative power beyond mere description. We also had a relatively small sample with limited variability. Given our small sample size and limited power, Bonferroni corrections to adjust for multiple statistical analyses were not used.

Directions for future research

Additional investigation with a larger, more representative sample would allow for higher-level analyses examining additional sociodemographic variables, such as race and ethnicity, in addition to SES indicators. Replication in other settings would contribute to the growing international literature on ASD. Future research could also examine child, family, and professional characteristics associated with higher and lower satisfaction levels with the diagnostic process and access to services. This information will aid policymakers in promoting not only collaborative relationships between parents and professionals, but also smoother diagnostic and service utility processes for parents and professionals.

Implications for practice

Results support an increase in attention to assessing satisfaction and barriers in families seeking healthcare and school-based services. By doing so, professionals can better support families facing multiple challenges in obtaining a diagnosis and services for their child, as well as potentially opening a dialogue for parents and professionals to collaborate in supporting the child being evaluated. In addition, in line with previous findings that parents in poverty are more likely to experience problems accessing services (Leiter & Krauss, 2004), more targeted outreach to low-income parents is needed. Lastly, results from the analysis support the implementation of competency training for paediatricians regarding how to better support parents as advocates for their children, as this may lead to improved parent–professional interactions and higher parental satisfaction ratings. Parents of children with ASD experience high levels of stress associated with the diagnostic process and access to services; reducing this stress would be a large public health benefit.

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References

Adler NE, Ostrove JM. Socioeconomic status and health: What we know and what we don't. Annals of the New York Academy of Sciences. 1999; 896:3–15.10.1111/j.1749-6632.1999.tb08101.x [PubMed: 10681884]

Ahern K. "Something is wrong with my child": A phenomenological account of a search for a diagnosis. Early Education and Development. 2000; 11:187–201.10.1207/s15566935eed1102_4

American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5. Arlington, VA: American Psychiatric Publishing; 2013.

Baum A, Garofalo JP, Yali AM. Socioeconomic status and chronic stress: Does stress account for SES effects on health? Annals of the New York Academy of Sciences. 1999; 896:131–144.10.1111/j.1749-6632.1999.tb08111.x [PubMed: 10681894]

Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology. 2006; 3:77–101.10.1191/1478088706qp063oa

Centers for Disease Control and Prevention. Prevalence of autism spectrum disorder among children aged 8 years –Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. Morbidity and Mortality Weekly Report, Surveillance Summaries. 2014; 63(SS02):1–21.

Cooper, JO.; Heron, TE.; Heward, WL. Applied behavior analysis. 2. Upper Saddle River, NJ: Pearson/ Merrill-Prentice Hall; 2007.

Croen LA, Grether JK, Selvin S. Descriptive epidemiology of autism in a California population: Who is at risk? Journal of Autism and Developmental Disorders. 2002; 32:217–224.10.1023/A:1015405914950 [PubMed: 12108623]

Dehon H, Larøi F, Van der Linden M. Affective valence influences participant's susceptibility to false memories and illusory recollection. Emotion. 2010; 10:627–639.10.1037/a0019595 [PubMed: 21038946]

Downs RC, Downs A. Practices in early intervention for children with autism: A comparison with the National Research Council recommended practices. Education and Training in Autism and Developmental Disabilities. 2010; 45:150–159.

Durkin MS, Maenner MJ, Meaney FJ, Levy SE, DiGuiseppi C, Nicholas JS, Schieve LA. Socioeconomic inequality in the prevalence of autism spectrum disorder: Evidence from a U.S. cross-sectional study. PLoS ONE. 2010; 5(7):e11551.10.1371/journal.pone.0011551 [PubMed: 20634960]

Elsabbagh M, Divan G, Koh YJ, Kim YS, Kauchali S, Marcín C, Fombonne E. Global prevalence of autism and other pervasive developmental disorders. Autism Research. 2012; 5:160–179.10.1002/aur.239 [PubMed: 22495912]

Fitzpatrick, R. Patient satisfaction. In: Baum, A.; Newman, S.; Weinman, J.; West, R.; McManus, C., editors. Cambridge handbook of psychology, health and medicine. Cambridge, UK: Cambridge University Press; 1997. p. 301-304.

Goin-Kochel RP, Mackintosh VH, Myers BJ. How many doctors does it take to make an autism spectrum diagnosis? Autism. 2006; 10:439–451.10.1177/1362361306066601 [PubMed: 16940311]

Harris JC. Autism risk factors: Moving from epidemiology to translational epidemiology. Journal of the American Academy of Child & Adolescent Psychiatry. 2012; 51:461–463.10.1016/j.jaac.2012.02.023 [PubMed: 22525951]

IBM Corp. IBM SPSS statistics for windows (Version 21.0) [Computer software]. Armonk, NY: Author; 2012.

Irvin DW, McBee M, Boyd BA, Hume K, Odom SL. Child and family factors associated with the use of services for preschoolers with autism spectrum disorder. Research in Autism Spectrum Disorders. 2012; 6:565–572.10.1016/j.rasd.2011.07.018

Keenan M, Dillenburger K, Doherty A, Byrne T, Gallagher S. The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. Journal of Applied Research in Intellectual Disabilities. 2010; 23:390–397.10.1111/j.1468-3148.2010.00555.x

Leiter V, Krauss MW. Claims, barriers, and satisfaction: Parents' requests for additional special education services. Journal of Disability Policy Studies. 2004; 15:135–146.10.1177/10442073040150030201

Liptak GS, Benzoni LB, Mruzek DW, Nolan KW, Thingvoll MA, Wade CM, Fryer GE. Disparities in diagnosis and access to health services for children with autism: Data from the National Survey of Children's Health. Journal of Developmental & Behavioral Pediatrics. 2008; 29:152–160.10.1097/DBP.0b013e318165c7a0 [PubMed: 18349708]

Mandell DS, Listerud J, Levy SE, Pinto-Martin JA. Race differences in the age at diagnosis among Medicaid-eligible children with autism. Journal of the American Academy of Child & Adolescent Psychiatry. 2002; 41:1447–1453.10.1097/00004583-200212000-00016 [PubMed: 12447031]

Mayes SD, Calhoun SL. Impact of IQ, age, SES, gender, and race on autistic symptoms. Research in Autism Spectrum Disorders. 2011; 5:749–757.10.1016/j.rasd.2010.09.002

Moh TA, Magiati I. Factors associated with parental stress and satisfaction during the process of diagnosis of children with autism spectrum disorders. Research in Autism Spectrum Disorders. 2012; 6:293–303.10.1016/j.rasd.2011.05.011

Schall C. Family perspectives on raising a child with autism. Journal of Child and Family Studies. 2000; 9:409–423.10.1023/A:1009456825063

United States Census Bureau. State & county quickfacts. 2010. Retrieved from http://quickfacts.census.gov/qfd/states/41/41039.html

Urdan, TC. Statistics in plain English. Mahwah, NJ: Erlbaum; 2001.

Woods JJ, Wetherby AM. Early identification of and intervention for infants and toddlers who are at risk for autism spectrum disorder. Language, Speech, and Hearing Services in Schools. 2003; 34:180–193.10.1044/0161-1461(2003/015)

Table 1

Correlations between SES and barrier variables from the thematic analysis (*N*= 46)

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1	Family income															
2	Maternal education	.02														
3	Insurance type	.31*	.14													
4	Medical service delivery	−.14	−.14	.00												
5	Limited services	.31*	−.01	−.27	.13											
6	Education service delivery	−.13	.17	−.11	−.22	−.21										
7	Public transportation	−.13	−.08	−.09	.11	−.11	−.09									
8	Time	−.17	.00	−.21	.14	.09	−.11	.81*								
9	Cultural stigma	−.17	−.19	−.02	.14	−.13	−.11	−.06	−.07							
10	Lack of public awareness	−.02	−.11	.04	−.02	−.15	.51**	−.07	−.08	−.08						
11	Ineffective screening tools	−.02	−.11	−.13	.16	.04	.08	−.07	−.08	−.08	.18					
12	Parental denial	−.10	−.14	−.16	−.11	−.19	.20	−.08	−.10	.16	.34*	.11				
13	Finances	−.07	−.48*	−.27	−.01	.17	.10	.16	.31*	.31*	.24	.04	.30*			
14	Paediatrician/professional	.09	−.17	.15	.58*	.23	−.22	−.02	−.11	.07	−.18	.13	−.03	.01		
15	No barriers reported	−.07	.33*	.00	−.49*	−.19	.14	.10	.03	−.17	−.19	−.19	−.24	−.31*	−.69*	

*$p < .05$, two-tailed.