

Disparities in Service Use Among Children With Autism: A Systematic Review

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abstract

CONTEXT: Research reveals racial, ethnic, and socioeconomic disparities in autism diagnosis; there is limited information on potential disparities related to other dimensions of services.

OBJECTIVE: We reviewed evidence related to disparities in service use, intervention effectiveness, and quality of care provided to children with autism by race, ethnicity, and/or socioeconomic status.

DATA SOURCES: Medline, PsychInfo, Educational Resources Information Clearinghouse, and the Cumulative Index to Nursing and Allied Health Literature were searched by using a combination of Medical Subject Headings terms and keywords related to autism, disparities, treatment, and services.

STUDY SELECTION: Included studies addressed at least one key question and met eligibility criteria.

DATA EXTRACTION: Two authors reviewed the titles and abstracts of articles and reviewed the full text of potentially relevant articles. Authors extracted information from articles that were deemed appropriate.

RESULTS: Treatment disparities exist for access to care, referral frequency, number of service hours, and proportion of unmet service needs. Evidence revealed that racial and ethnic minority groups and children from low-income families have less access to acute care, specialized services, educational services, and community services compared with higher-income and white families. We found no studies in which differences in intervention effectiveness were examined. Several studies revealed disparities such that African American and Hispanic families and those from low-income households reported lower quality of care.

LIMITATIONS: The body of literature on this topic is small; hence it served as a limitation to this review.

CONCLUSIONS: The documented disparities in access and quality of care may further identify groups in need of outreach, care coordination, and/or other interventions.



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WHAT'S KNOWN ON THIS SUBJECT: Individuals with autism spectrum disorder (ASD) and their families experience significant disparities regarding obtaining timely ASD diagnosis on the basis of factors such as race, ethnicity, and household income. Documented disparities are less well explored for service access.

WHAT THIS STUDY ADDS: Children and families encounter race-, ethnicity-, and income-based service disparities. Families of color and lower income report less service access and quality and higher unmet service needs than their white, higher-resourced counterparts. Research evaluating disparities in ASD-related treatment is insufficient.

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Autism spectrum disorder (ASD) is a neurodevelopmental disorder that affects 1 in 59 children in the United States.¹ It is characterized by “persistent deficits in social communication and social interaction and restricted, repetitive patterns of behavior, interests, or activities.”² Children with ASD often require a variety of services from multiple systems, such as speech, behavioral, and occupational therapies; specialized medical care; and special education. Families frequently take responsibility for navigating these complicated service systems, and they can experience challenges both in obtaining an accurate and timely diagnosis and in accessing needed care.³ Requirements and constraints of the service system may interact with family characteristics, such as race, ethnicity, and socioeconomic status (SES), to contribute to service disparities.

In a seminal report from the Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, the authors documented the presence and deleterious effects of inequalities in health care by race, with African American and Hispanic families less likely to receive appropriate care, resulting in a lower quality of health care services.⁴ Numerous studies have been published since that time, providing further evidence of the negative consequences of disparities in health care access and delivery.⁵

There is a growing body of literature that reveals racial, ethnic, and socioeconomic disparities in ASD diagnosis, but little is known about service access and care. For the purposes of this literature review, which is focused on disparities in ASD services and care, we preserved the terminology on race, ethnicity, and SES used by the original authors of each cited article. The Centers for Disease Control and Prevention estimated that ASD prevalence is significantly higher among non-Hispanic white children

aged 8 years (17.2 per 1000) versus non-Hispanic African American children (16.0 per 1000) and Hispanic children (14.0 per 1000) aged 8 years,⁶ although it is important to note that this likely reflects diagnostic disparities rather than true differences in prevalence. These disparities are also indicative of diagnostic delays. Regarding the timing of diagnostic evaluation, the percentage of children with the youngest ages at first evaluation was highest for non-Hispanic white children (45%) compared with non-Hispanic African American children (40%) and Hispanic children (39%).⁶

As early as 2002, Mandell et al⁷ reported that on average, white children received an ASD diagnosis at 6.3 years of age, compared with 7.9 years for African American children. In 2007, Mandell et al⁸ reported racial and ethnic differences in the timely and accurate identification of ASD whereby African American children were 2.6 times less likely than white children to receive an ASD diagnosis on their first specialty care visit. Children who were African American or Hispanic were less likely than non-Hispanic white children to have documented ASD.⁹ Magaña et al,¹⁰ in comparing Hispanic and non-Hispanic children diagnosed with ASD, found that Hispanic children were diagnosed almost one year later than non-Hispanic white children. Zuckerman et al¹¹ reported that Hispanic families with limited English proficiency were more likely to experience barriers to ASD diagnosis than non-Hispanic white families. Further evidence from Valicenti-McDermott et al¹² revealed that children of Hispanic and African American origin, foreign-born children, and children born to foreign mothers were likely to be diagnosed later than white children.

Diagnostic disparities are also influenced by other family characteristics such as SES (which is a social standing measured by

income, education, and occupation) and language or country of origin.¹³ In 2008, Liptak et al¹⁴ examined income level, in addition to race and ethnicity, using data from the National Survey of Children's Health of 2003 and 2004. They found that the prevalence of ASD was lower for Hispanic children (26 of 10 000) than for non-Hispanic children (51 of 10 000); white and African American children had comparable rates, and the lowest preschool rate for autism occurred in children from low-income households (16 of 10 000).¹⁴ Disparities in parental education play a role as well, with children of highly educated parents being diagnosed earlier than those of parents without a college degree.¹⁵ These patterns are concerning given that late diagnosis has serious consequences, such as reduced access to appropriate services, resulting in fewer opportunities for optimal outcomes.¹⁵

Literature synthesizing disparities in ASD service access and care is limited. However, there are substantial racial, ethnic, and income-related disparities in service use and quality documented in other areas, including child mental health services, child health care, and care for children with chronic medical conditions.¹⁶⁻¹⁸ In the context of these broader disparities and the knowledge about disparities in ASD diagnosis, a review of patterns of service use in ASD is needed.

The purpose of this systematic review was to identify information related to the following questions:

- Key question 1: What are the disparities in service use among children with ASD by race, ethnicity, and/or SES?
- Key question 2: Are there differences in the effectiveness of interventions for children with ASD by race, ethnicity, and/or SES?
- Key question 3: Are there differences in the quality of care provided to

children with ASD by race, ethnicity, and/or SES?

Definitions of elements included in the key questions are as follows:

service use: outcomes related to service uptake, intervention retention or attrition, and service duration;

intervention effectiveness: child- and family-level primary and secondary outcomes, as defined by the article authors; examples could include child language, challenging behavior, family functioning, etc; and

quality of care: indicators of intervention quality, including caregiver-perceived quality of interventions and providers, as well as perceived unaddressed needs.

Theoretical support for conducting this review was provided by the social ecological model. Bronfenbrenner¹⁹ proposed this model for describing the context in which human development occurs. His model consists of layers of influence in the developmental process, including “micro” (family and siblings and home), “meso” (one’s neighborhood, school, and church), “exo” (the larger social system, such as health care, police, and the welfare system), and “macro” (includes cultural and societal values and laws).²⁰ This theory helps to explain the developmental experiences of different groups and serves as a basis for beginning to understand the disparities that may exist in the diagnosis and treatment of autism. The social ecological model has been used to provide context to health disparities in previous research because the factors affecting how families interact with each layer of the system of services are heavily influenced by culture and potential discrimination.²¹

METHODS

The Autism Speaks Autism Treatment Network and the Autism Intervention

Research Network on Physical Health, funded by the Health Resources and Services Administration, formed a workgroup of experts (consisting of the author team) with content-area expertise as well as experience working with individuals from diverse racial and ethnic backgrounds and SESs to conduct a literature search and subsequent review to address the key questions outlined above.

Search Strategy

We searched Medline through Ovid, PsycINFO, Educational Resources Information Clearinghouse, and Cumulative Index to Nursing and Allied Health Literature, as well as GoogleScholar and PubMed, for English-language articles published before the search date. The search was conducted on September 1, 2016, with no limit on the publication date. Search terms included a combination of Medical Subject Headings appropriate for each database and keywords relevant to ASD; racial, ethnic, and socioeconomic or income disparities; treatment; and services (see Search Terms and Search Strategy section of the Supplemental Information for the search strategy with all Medical Subject Headings terms and keywords used). We worked with a librarian from the Massachusetts General Hospital Treadwell Library to ensure the integrity and thoroughness of our literature search. After the initial search, all articles were imported into reference manager software, and all duplicates were removed. The reference lists of all included articles, as well as recent narrative and systematic reviews and meta-analyses that looked at disparities and ASD but did not directly address our research questions, were manually reviewed to identify any articles that our literature search may have missed.

Study Selection

The initial literature search identified 175 articles. Reviewers

independently screened the titles and abstracts for relevance to our review. Then the 5-member workgroup reviewed full-text articles for inclusion or exclusion on the basis of the review’s key questions as outlined in the introduction (see Fig 1); an article needed to address one of our key questions. Any questionable articles were discussed as a group, and a decision was made by consensus. Inclusion criteria comprised both quantitative and qualitative data on disparities. For quantitative data, disparities were defined as unfavorable outcomes for a nondominant group, as compared with data from a dominant group. For qualitative data, disparities were defined as lived experiences in which the outcomes described in the key questions were perceived as influenced by being a member of a marginalized group. Search terms are included in the Search Terms and Search Strategy section of the Supplemental Information. All reviews were completed by 2 reviewers, first independently and then through consensus.

Data Abstraction

Using a standardized form (see Data Abstraction Table in the Supplemental Information), reviewers independently abstracted relevant data related to key questions from all articles that met inclusion criteria. The data abstraction form was finalized with workgroup consensus and included data elements relevant to ensuring the integrity of the review. The following data were abstracted: author; publication year; sample size (*N*), primary diagnosis of the study sample, age, study setting, research design, types of disparities addressed, and results.

RESULTS

A total of 11 articles that met all eligibility criteria and addressed at least one of the key questions were identified (see Tables 1 and 2). Ten of 11 articles addressed key question 1,

no articles addressed key question 2, and 4 articles addressed key question 3. Three articles addressed both key questions 1 and 3. Although the scope of the review did not restrict on the basis of country, all articles represented studies completed in the United States.

Service Access and Use

For key question 1, much of the identified literature addressed disparities in service access and use by race, ethnicity, or SES. Main results, as well as additional findings, are shown in Table 1.

In 9 of the 10 articles, the authors examined disparities in service access or service use by race or ethnicity. The consensus among all articles is that racial and ethnic minorities are found to be less likely to have access to, and thus use, health care and treatment services.^{10,14,22-29} Within the health care setting, Hispanic children with ASD were found to have difficulty using services because of language barriers, have higher odds of not having a personal doctor, and have increased difficulty receiving referrals compared with non-Hispanic white children.^{10,22,27,28} African American and Hispanic children had significantly lower use of specialty services (gastrointestinal and nutrition services, neurology, and psychiatry and psychology) and were less likely to access specialty procedures, such as a pH probe, stool studies, an abdominal ultrasound, a colonoscopy, an endoscopy, an EEG, a head computed tomography scan, a brain MRI, a sleep study, a psychiatric evaluation, neuropsychiatric testing, and developmental screening, in these service areas compared with non-Hispanic white children.^{14,23} Additionally, African American and Hispanic families had more difficulty receiving acute care than non-Hispanic white children.¹⁴

Disparities in accessing and using treatment services were also reported by race or ethnicity. Treatment

services included school-based services, such as the Individualized Education Program (IEP), ASD-specific therapies, access to respite care, and other therapies such as speech and language therapy (SLT) and occupational therapy (OT), and community-based therapies such as recreational programs.^{10,14,22-29}

Hispanic children were found to be less likely to receive an IEP than non-Hispanic white children and less likely to receive OT and SLT compared with non-Hispanic children of all races.^{24,25} Asian American children were also shown to be less likely to receive OT and SLT compared with white children.^{24,25} Hispanic children were less likely to receive ASD-specific therapy, have access to respite care, and take part in recreational programs than non-Hispanic white children.¹⁰

SES, defined by income-level classification or a percentage of the federal poverty level (FPL), and maternal education were examined in 7 of the 10 studies. Like disparities by race and ethnicity, SES disparities were found with families with lower SES reporting less access to and use of health care and treatment services rather than with families with higher SES. Children with ASD from low-income families were less likely to use health care services, reported more difficulty receiving a referral to specialty services, and had lower rates of hospitalization than middle- and high-income families.^{14,26}

Children from families with incomes <200% of the FPL were less likely to have a personal doctor than those with incomes at or >200% of the FPL.²⁷ Additionally, caregivers with a higher SES were found to be more likely to enroll their child in applied behavior analysis (ABA) therapy and OT than those with lower SES.²⁵ Parent education level was shown to be most related to receipt of treatment services, with higher levels of parental education associated with higher levels of service use.¹⁰

Children of parents with more than a high school education were more likely to receive an IEP, OT, ABA, and other ASD-specific therapies than children of parents with less than a high school education.^{10,25,26,29}

Effectiveness of Interventions

For key question 2, we found no evidence of examined disparities in intervention effectiveness based on racial, ethnic, or socioeconomic disparities.

Quality of Care

For key question 3, findings on differences in quality of care by race, ethnicity, or SES were reported in 4 of 11 included studies. Three of these 4 studies also addressed key question 1.

In all studies, disparities by ethnicity were examined, and in 2 studies, disparities by race were also examined. The authors of 1 study examined SES defined by income level as a percentage of the FPL.

Lower-quality care was reported by African American and Hispanic families compared with non-Hispanic white families.^{8,22,27,30} African American and Hispanic families described a poorer quality of care resulting from a lack of cultural competence among providers, meaning these families reported that their providers did not understand or were not sensitive to their values or cultural beliefs. In addition, African American and Hispanic families reported that their doctors did not spend enough time with them, that they were not made to feel like a partner in their child's health, and that they were not provided enough information, compared with non-Hispanic white families.^{27,28,30}

African American parents of children with ASD also reported that their children did not receive family-centered care, compared with all other groups, and Hispanic parents reported higher unmet needs related to routine and preventive care than

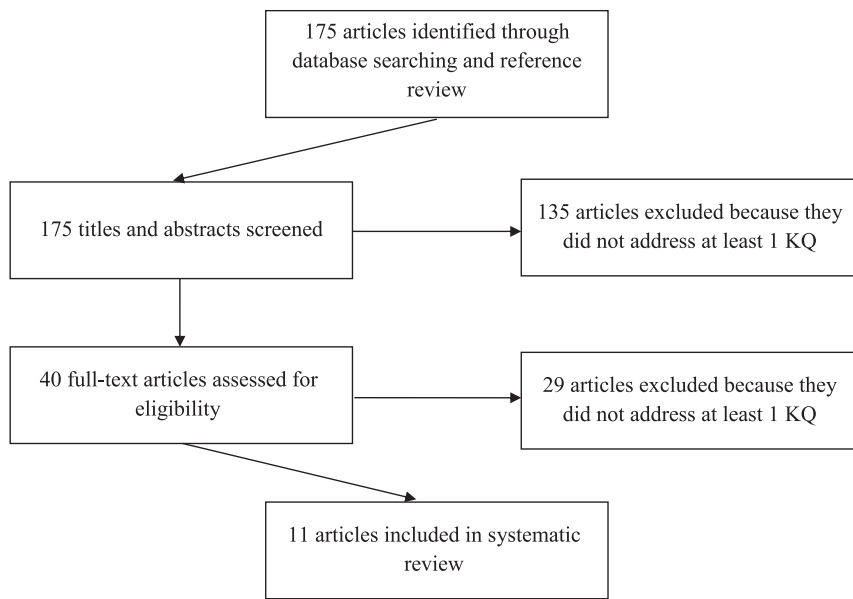


FIGURE 1
Systematic multistage review process. KQ, key question.

all other groups.³⁰ Families with an income <200% of the FPL were more likely to report lower quality of care than families with an income at or above this level.²⁷

DISCUSSION

In the context of well-documented diagnostic disparities in ASD, we systematically reviewed the impact of race, ethnicity, and SES on service access and quality in this population. Search terms related to race, ethnicity, and income emphasized nomenclature common to reporting conventions in the United States. Although there is overlap in this terminology with that used in other parts of the world, it is possible that our selected parameters did not fully capture the range of possible cultural and income-related search terms.

To our knowledge, this is the first review article to be focused specifically on service- and treatment-related disparities by race, ethnicity, and SES in children with ASD. The most commonly reported findings were related to service access and use (key question 1),

indicating that racial and ethnic minorities have less access to and lower use of relevant health care and treatment services, as compared with their white, higher-resourced counterparts.

These findings are similar to patterns of disparities in service use that have been highlighted in individuals with other conditions.³¹ Knowledge of existing services has been cited as a barrier to accessing ASD services, which speaks to the need for dissemination of information about services in community settings that reach all potential consumers.³² For example, providers may need to make a special effort to educate families about available resources, and dissemination of knowledge about services should be done in a way that is targeted specifically to diverse consumers, in ways that are culturally responsive, and in languages that are accessible to community members.³¹ To address disparities, health care systems might provide more services for families in locations where they may feel more comfortable and trusting, would encounter fewer logistic barriers, and are more likely

to encounter providers who are culturally and linguistically matched, which can enhance outcomes and treatment engagement.^{33,34} Because most services for children with ASD are delivered via outpatient models, logistic barriers, such as transportation, child care, and job accommodations, must be addressed to enhance families' ability to appropriately access services. Exploring potential treatment barriers with families may help enhance a sense of trust and encourage collaborative problem-solving between families and providers.

Also captured under key question 1, disparities in effective referrals and service use for Hispanic children with ASD were specifically related to language barriers. In patient-provider interactions, meeting the needs of families who are racially and linguistically diverse may require additional strategies, such as recruiting diverse providers, facilitating families' knowledge of and access to interpreter services, and ensuring that materials are available in multiple languages.

Intriguingly, none of the identified studies examined differences in intervention effectiveness by race, ethnicity, or SES (key question 2); this is an understudied area within the disparities literature that is in need of attention, particularly given criticisms regarding the lack of diversity in research studies on treatments related to ASD and, more broadly, in the psychotherapy literature.^{35,36} Given the heterogeneity of the ASD population, the potential barriers to access to evidence-based practices, and the lack of knowledge of appropriate dosing for therapies, it may in fact be premature to expect an adequate body of research in intervention effectiveness and disparities. Research on potential disparities in treatment effectiveness is critical because racial and ethnic disparities in intervention efficacy

TABLE 1 Key Question 1: What Are the Disparities in Service Use Among Children With ASD From Different Racial and/or Ethnic Backgrounds and/or SESs?

Author, Year	Sample Size (N) and Diagnosis	Study Sample Age, y	Study Setting	Research Design	Types of Disparities Addressed	Results
Blanche et al, ²² 2015	28 (15 parents; 13 children with ASD)	3–8	Home and clinic	Descriptive qualitative analysis	Ethnicity	Because of language barriers, many Hispanic caregivers faced troubles when using services. Hispanic caregivers often experienced the following: (1) difficulties in dealing with the diagnosis (cultural differences), (2) difficulties in dealing with stigma and isolation from family and the community (cultural differences), and (3) difficulties in understanding the role of mothers in changing family routines.
Broder-Fingert et al, ²³ 2013	3615 children with ASD	2–21	n/a; survey	Secondary analysis of medical record data	Race, ethnicity	There were significant racial and ethnic differences in subspecialty visits and procedures (such as GI, neurology, and psychology). Specialty visits: African American children had fewer subspecialty visits compared with white children. African American and Hispanic children had significantly lower use of subspecialty care in GI nutrition, neurology, psychiatry, and psychology compared with non-Hispanic white children. Specialty procedures: African American children and Hispanic children were significantly less likely to access specialty procedures compared with non-Hispanic white children.
Harstad et al, ²⁴ 2013	662 children with ASD	6–17	n/a; survey	Secondary data analysis of national survey	Race, ethnicity, SES	Hispanic children were less likely to receive an IEP compared with non-Hispanic white children. Above-high school maternal education was associated with IEP receipt. Disability severity was not associated with IEP receipt. Perceived need for coordination of care was associated with IEP receipt.
Irvin et al, ²⁵ 2011	137 children with ASD	3–5	Classroom and home	Cross-sectional study	Race, ethnicity, SES	There were associations between race and ethnicity and outcomes. Hispanic children received less SLT and OT compared with non-Hispanic children. Asian American children received less OT than white children. Caregivers with a higher SES were more likely to enroll their child in ABA services and private OT than those with lower SES. High-stressed caregivers had a lower probability of using OT across all races compared with low-stressed caregivers.
Liptak et al, ¹⁴ 2008	495 children with ASD	0–17	n/a; survey	Secondary data analysis of national survey	Race, ethnicity, SES	Children from poor families were less likely to use physician services and had more difficulty getting a referral to a specialist when compared with children from middle- or high-income families. African American and Hispanic families indicated increased difficulty in getting acute care or needed advice by phone than non-Hispanic white families. Hispanic children reportedly had more problems seeing a specialist than non-Hispanic white children. The prevalence of receiving an ASD diagnosis was significantly lower for Hispanic children compared with non-Hispanic children. Diagnostic rates between African American

TABLE 1 Continued

Author, Year	Sample Size (N) and Diagnosis	Study Sample Age, y	Study Setting	Research Design	Types of Disparities Addressed	Results
Lokhandwala et al, ²⁶ 2011	5186 individuals with ASD; 20 744 controls	0–100	n/a; survey	Descriptive analysis of national survey	SES	and white children were similar. Hispanic children were often diagnosed at a later age than non-Hispanic white children. Hispanic parents rated their children's autism as more severe compared with non-Hispanic parents. A significantly higher proportion of hospitalizations among individuals with autism were those from families with annual incomes >\$63 000 (81.7 of 100 000 vs 70.89 of 100 000). Hospitalizations of individuals with autism were significantly more likely to occur in hospitals in urban settings and the Northeast. There was a higher proportion of individuals with autism who had public insurance when compared with typically developing peers. However, among this population, hospitalization rates were higher for those with private insurance than public insurance. The length of stay was significantly longer for those with autism compared with those without autism.
Magaña et al, ²⁷ 2012	1959 children with ASD and 2455 children with other developmental disabilities	0–18	n/a; survey	Secondary analysis of national survey	Race, ethnicity, SES	Hispanic children with autism and other developmental disabilities had higher odds of not having a personal doctor compared with non-Hispanic white children with autism and other developmental disabilities. Independent of autism diagnosis, children from families with an annual income <200% of the FPL were less likely to have a personal doctor than families with incomes at or >200% of the FPL. The disparities between African American and white children for not having a personal doctor were greater for children with autism than for those with other developmental disabilities.
Magaña et al, ¹⁰ 2013	104 individuals with ASD	2–22	Home	Cross-sectional study	Ethnicity, SES	Hispanic children were less likely to receive recreational programs, psychological services, respite care, and intensive autism therapy than non-Hispanic white children. Overall, Hispanic children had a greater number of unmet service needs compared with non-Hispanic white children. A higher number of services used was associated with higher levels of parental education. A higher number of services used was associated with having more sources of knowledge.

TABLE 1 Continued

Author, Year	Sample Size (N) and Diagnosis	Study Sample Age, y	Study Setting	Research Design	Types of Disparities Addressed	Results
Parish et al, ²⁸ 2012	1755 children with ASD and 2659 with other developmental disabilities	0–18	n/a; survey	Secondary analysis of national survey	Ethnicity	Hispanic children with ASD and other developmental disabilities were more likely to have difficulty using services, had problems getting referrals, and were less likely to have a personal doctor compared with non-Hispanic white children with ASD and other developmental disabilities. Hispanic children were more likely to have no insurance than non-Hispanic white children.
Thomas et al, ²⁹ 2007	383 children with ASD	0–11	n/a; survey	Secondary analysis of community survey	Race, ethnicity, SES	Racial and ethnic minorities were less likely to use various treatment services (psychologist, case manager, etc) than individuals who identified as white. Parents who had a college education were more likely to use services for their children with ASD than those without a college education. Parents with higher levels of stress were more likely to use services for their children with ASD than those with less stress. Families covered by Medicaid or other public insurers were more likely to use services considered medically necessary than those with private insurance.

GI, gastrointestinal; n/a, not applicable.

have been preliminarily documented in other populations.³⁶ Perhaps more importantly, because most well-designed intervention studies in ASD have not analyzed efficacy by factors such as race, ethnicity, and income, we have little evidence regarding the potential external validity of treatments that are considered to be evidence based.

The focus on identifying potential disparities regarding intervention quality (key question 3) revealed that families of children with ASD from nonwhite backgrounds were less likely to report receiving quality health care compared with other groups. Limited receipt of family-centered care, which included a lack of cultural responsiveness from providers, has the potential to interfere with the relationship and trust between families and professionals. This is unsurprising because issues related to trust and provider-patient relationships are often reported as barriers to effective

engagement in treatment.³⁷ Shifts toward cultural responsiveness generally require multilevel intervention, so systems-wide education in, and standards for, cultural competence of those delivering ASD treatment may help break down issues of trust and stigma that are common barriers to seeking treatment.³⁸ Provider education is critical, particularly education that is focused on promoting self-reflection (eg, assessing one’s own potential judgments and bias) and knowledge of cultural issues that may cut across diverse groups.³⁹ For example, facilitating cultural responsiveness may require explicit education around prejudice and racism (and other “-isms”) as well as perceptions of family roles, beliefs about medical conditions, and preferred communication styles.⁴⁰

Finally, although we focused specifically on service and treatment inequalities for this review, the identified disparities should not be

considered independent of diagnostic disparities. Diagnostic delays and misdiagnoses have significant downstream effects for families’ ability to engage services, so our findings should be considered in the context of the existing literature on diagnostic disparities as well.^{10,29,41–43}

Limitations

The body of literature on this topic is small, which was a limitation to this review. We limited our search to disparity-related keywords to ensure that between-group comparisons were included as part of the analyses. There is, however, a potential for omission bias because investigators may not have reported a lack of difference in service use due to race and/or ethnicity. Therefore, this review is focused on studies in which there was a noted disparity, possibly representing an overestimate bias. Additionally, several of the articles cited are from the National Survey for

TABLE 2 Key Question 3: Are There Differences in the Quality of Care Provided to Children With ASD From Different Racial and/or Ethnic Backgrounds and/or SESs?

Author, Year	Sample Size, <i>N</i>	Study Sample Age, <i>y</i>	Study Setting	Research Design	Types of Disparities Addressed	Results
Blanche et al., ²² 2015	28 (15 parents; 13 children with ASD)	3–8	Home and clinic	Descriptive qualitative analysis	Ethnicity	Lack of professionals who understand Hispanic family values and cultural beliefs, as well as language barriers, made treatment difficult. There was often a lack of information available in Spanish for Hispanic families.
Magaña et al., ²⁷ 2012	1959 children with ASD and 2455 children with other developmental disabilities	0–18	n/a; survey	Secondary analysis of national survey	Race, ethnicity, SES	African American and Hispanic parents reported higher odds of their doctor not spending enough time with them, not being sensitive to family values and customs, not making them feel like a partner in their child's health, and not providing enough information compared with non-Hispanic white parents. Families with an annual income <200% of the FPL were more likely to report that their child's doctor did not spend enough time with them or listen to them than those at or >200% of the FPL. Parents of children with autism were more likely to report that their doctor did not spend enough time with their child, that their doctor did not listen, that their providers were not sensitive to the family's values and customs, and that doctors did not provide enough information than parents of typically developing children. The disparities between African American and white children in reporting having a doctor who did not spend enough time with them was greater for children with autism than for those with other developmental disabilities. Likewise, the difference in reports of having a doctor who did not listen between Hispanic and white children was greater for children with autism than for those with other developmental disabilities.
Montes and Halterman, ³⁰ 2011	35 386 children with ASD	0–17	n/a; survey	Secondary analysis of national survey	Race, ethnicity	Fewer parents of African American children with ASD reported that the doctor spent enough time with their child, that the doctor was sensitive to their values and customs, and that the doctor helped them feel like a partner in the care of their child compared with parents of white children with ASD. African American parents of children with ASD most commonly reported that their child sometimes or never received family-centered care as compared with all other studied groups. Fewer parents of white and African American children with ASD reported receiving family-centered care compared with those whose child had special needs other than ASD.
Parish et al., ²⁸ 2012	1755 children with ASD and 2659 children with other developmental disabilities	0–18	n/a; survey	Secondary analysis of national survey	Ethnicity	Hispanic children with ASD and other developmental disabilities were more likely to have providers who (1) did not spend enough time with them, (2) were not culturally sensitive, and (3) did not make the parent(s) feel like a partner compared with non-Hispanic white children. Hispanic children were also more likely to have unmet routine or preventive care needs.

n/a, not applicable.

Children's Health or the National Survey for Children with Special Health Care Needs, which may indicate that they are not truly independent findings. In addition, although we focused on articles from peer-reviewed journals, our review did not include an assessment of the quality of the articles reviewed because this is an understudied area. Another possible limitation is the use of studies based on parent report that may be subject to bias. Use of administrative data, compared with controlled samples, also could serve as a possible limitation. Finally, a search that included a manual review of abstract text for race, ethnicity, and SES as treatment moderators may have yielded results for key question 2, although the lack of additional studies cited in the articles we reviewed suggests

that all relevant articles were included.

Future Research

The evidence supporting racial, ethnic, and economic disparities in ASD diagnosis and service access is strong and has been replicated across multiple studies. At this juncture, the onus is on investigators conducting intervention research in ASD to explicitly recruit and report on diverse samples in their clinical trials. Evaluation of race, ethnicity, and family income as potential mediators and moderators of treatment may help shed light on whether we should expect differential outcomes for families who are traditionally underrepresented in research. These findings, in turn, could help inform the development of interventions that are responsive to the individual and

family's circumstances, with a specific emphasis on reducing barriers to service access.

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ABBREVIATIONS

ABA: applied behavior analysis
ASD: autism spectrum disorder
FPL: federal poverty level
IEP: Individualized Education Program
OT: occupational therapy
SES: socioeconomic status
SLT: speech and language therapy

Drs Smith, Gehricke, Iadarola, and Kulthau participated in conceptualizing and designing the study and the data collection instruments, participated in data collection (review of abstracts and full studies), drafted the initial manuscript, and reviewed and revised the manuscript; Ms Wolfe participated in conceptualizing and designing the study and the data collection instruments, participated in coordinating data collection (literature search), participated in data collection (review of abstracts and full studies), and contributed to writing and editing the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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