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## Parental perceptions of ASD in Latinx and Black sociocultural contexts: Systematic review

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**Parental perceptions of ASD in the Latinx and Black sociocultural context: A  
systematic review**

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### **Abstract**

Parents of children with autism spectrum disorders (ASD) generally face challenges in accessing timely diagnostic and treatment services; but the extent of these challenges varies by race, ethnicity, and culture (Bishop-Fitzpatrick & Kind, 2017). This **systematic** review examines social and parental perceptions of ASD within Latinx and Black American communities, which are burdened by ASD-related healthcare disparities. We included 50 articles that met eligibility criteria (32 published within the past five years). Findings indicated that interconnections with family members and religious groups promoted positive coping; parents also reported positive impacts of having a child with ASD. Families reported greater limits to accessing information about the causes and course of ASD, more inaccurate beliefs about ASD, higher levels of ASD-related stigma, and more negative experiences with healthcare providers, relative to Whites. Experiences were further shaped by familial, religious, and gender roles, some of which increased maternal burden. These experiences increase healthcare access disparities for Latinx and Black Americans with ASD. Conclusions are limited by a significant under-representation of Black Americans, and by a systematic failure to address the specific needs of racial and ethnic minorities. We discuss clinical implications and outline a strategic plan for reducing these disparities.

*Keywords:* autism spectrum disorder; barriers to treatment; African American; Latino; healthcare disparities

**Parental perceptions of ASD in the Latinx and Black sociocultural context: A  
systematic review**

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by deficits in social communication, the presence of repetitive behaviors and interests, and atypical sensory processing. Although the disorder is equally prevalent across racial and ethnic groups (Christensen, Braun, Baio, Bilder, Charles, Constantino & Lee, 2018), research has repeatedly documented inequities in the diagnosis and treatment of non-White groups (Bishop-Fitzpatrick & Kind, 2017; Angell, Empey & Zuckerman, 2018). Latinx<sup>1</sup> and Black Americans<sup>2</sup> are less likely than White children to have a documented diagnosis (Baio et al., 2018; Mandell et al., 2009); they also receive these diagnoses later (Mandell, Listerud, Levy, & Pinto-Martin, 2002; Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011; Magaña, Lopez, Aguinaga, & Morton, 2013), and are less likely to be seen by specialists (Broder-Fingert, Shui, Pulcini, Kurowski, & Perrin, 2013) or to receive coordinated care and family-centered treatment (Jarquin, Wiggins, Schieve, & Van Naarden-Braun, 2011; Magaña et al., 2012). Latinx children experience a delay between diagnosis and treatment (Magaña et al., 2013), and Black American children are more than twice as likely to be misdiagnosed (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007), when compared to White children. These disparities carry significant clinical consequences; parents of non-White children with ASD report reduced access to healthcare and less satisfaction with that healthcare (Liptak et al., 2008; Magaña, Parish, Rose, Timberlake, & Swaine, 2012).

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<sup>1</sup> The term “Latinx” is used rather than Latino/Latina, as a more gender inclusive term, especially for LGBT and gender-nonconforming individuals. This review focuses on people from Spanish-speaking countries in Latin-America; it does not include Hispanics from other regions.

<sup>2</sup> “Black American” is used to denote the multi-ethnic nature of the Black community in the U.S.; for instance, African and Afro Caribbean immigrants are often included in the Black/African American group despite different cultural and ethnic backgrounds. As used here, the term does not include Black Latinxs.

Latinx and Black Americans are the largest non-White groups in the U.S. (U.S. Census Bureau, 2017), accounting for approximately 30% of the U.S. population; according to projections from the Pew Research Center, by 2055, less than half of the U.S. population will consist of “non-Hispanic Whites” (“Modern Immigration Wave,” 2015). While all families interpret children’s behaviors, strengths, and weaknesses in unique ways, their understanding of psychological concerns is strongly influenced by their cultural backgrounds (Bussing, Schoenberg, & Perwien, 1998; Yeh, Hough, McCabe, Lau, & Garland, 2004). For instance, non-White parents are less likely than White parents to endorse physical causes of developmental disorders (Yeh et al., 2004) or to use medical language in discussing their children’s difficulties (Bussing et al., 1998). Non-White parents of children with ASD endorse similar barriers to services as do White parents; however, the extent of and reasons for these barriers differ. There is some overlap between Latinx and Black American caregivers’ perceptions of issues related to race and ethnicity, and their communities’ perceptions of ASD (Stahmer et al., 2019). Research also shows that socio-cultural factors influence how and when families seek diagnostic and intervention services (Dardennes, Anbar, Prado-Netto, Kaye, Contejean & Anbar, 2011; Singh and Bunyak, 2020; Hebert & Koulouglioti, 2010; Mandell & Novak, 2005). In a society that is rapidly diversifying, it is critical that we understand the specific socio-cultural and systemic factors that impact access to services for these communities.

Non-White individuals have been generally underrepresented in research on ASD (Hilton et al., 2010; Kalsner et al., 2018; West et al., 2016); inadequate reporting of race and ethnicity is also common. For example, non-White participants may be lumped together and described as “Other,” which, among other challenges, makes it impossible to meaningfully include them in meta-analyses (Pierce et al., 2014; Wolery & Garfinkle, 2002). This historical lack of research

has limited our understanding of the specific, sociocultural needs and experiences of these communities; fortunately, the last few years has seen a surge in research. The current review provides an updated perspective, focusing on parental and community perceptions of the causes and course of ASD; experiences with stigma; protective factors; and religious, family, and gender values, as they relate to Latinx and Black Americans. We also review reports of experiences with healthcare professionals. While health disparities reflect the impact of carrying any of a wide variety of marginalized identities (e.g., having a lower socioeconomic status, living in a rural area, or being non-White), the present work focuses specifically on those who identify as Latinx or Black American. In this paper, we 1) present a **systematic** review of parental and community perceptions of ASD in Latinx and Black American communities, 2) discuss the clinical implications of these perceptions, and 3) provide recommendations to facilitate better research and clinical practice, and to increase equitable access to care.

### **Approach of the current review**

The studies included in this review encompass a broad variety of factors that impact access to and quality of services. Against this background, we performed a **systematic** review following PRISMA guidelines; see Figure 1. The factors discussed in this review were chosen based on the following criteria: 1) they are important cultural values for the target populations, 2) they have been empirically linked to ASD-related healthcare disparities, and/or 3) they have potential to inform clinical practice. We performed a comprehensive review of the literature using *PsychInfo*, *PubMed*, *EBSCO Dissertation Repository*, and *Google Scholar*. Key search terms were: [ASD; autism; Asperger] and [Latin\*; Hispanic; African American; African; Black], conjoined with: parental beliefs; perceptions; disparities; barriers; knowledge; faith; vaccines; coping; stress. Articles were included if they met the following criteria: 1) the sample included

Latinx or African/Black American participants (or both); 2) the primary focus was on ASD; 3) the research addressed parental or community perceptions of ASD; 4) the research was conducted in the U.S.; and 5) the study discussed any of the following topics: perceptions about the causes/course of ASD, knowledge of ASD, family stigma, family stressors, or the roles of religious, family, and gender values. The search was limited to articles between 2005 to 2019. After removing duplicates and screening titles and abstracts for eligibility, we were left with a total of 45 peer-reviewed articles and 5 dissertations, which were included in this review. Dissertations were included for the Black American group only due to limited research.

### **FIGURE 1 HERE**

The studies included in this review were assessed for quality using the *Let Evidence Guide Every New Decision (LEGEND)* system (Clark, Burkett, & Stanko-Lopp, 2009). After independently evaluating each study, the first two authors conferred and compared quality ratings (i.e., *good*, *moderate*, *lesser*). Inter-rater evaluation disagreements were discussed and resolved before finalizing quality ratings. Of the studies included, 48% achieved a *good* quality rating, 38% were deemed *moderate* and 14% were considered of *lesser* quality; ratings were addressed in the discussion of findings below. Table 1 presents these quality ratings and describes the methodologies and study samples included in this review.

### **TABLE 1 HERE**

Overall, this review provides a specific, comprehensive overview of key factors that contribute to ASD-related health inequities in Latinx and Black American communities in the U.S. We highlight communities and parent perceptions of the causes, course, and red flags of ASD; ASD-related feelings of stigma; family impact; protective factors (including religion, families and gender roles); and patient-provider relationship quality as they relate to ASD

diagnosis and treatment in these populations. The Discussion presents practical steps for reducing stigma and facilitating better access to healthcare services in members of Latinx and Black American communities.

### **Beliefs about the etiology of ASD**

Studies of Latinx community members' beliefs about the etiology of ASD have yielded conflicting results. Voelkel and collaborators (2013) surveyed 168 Latinx community members and found that while most (70%) knew that vaccines do not cause ASD, many (46%) believed that emotional trauma played a significant role; most (64%) did not understand the role of genetics (Voelkel, LeCroy, Williams, & Holschuh, 2013). Similarly, a qualitative interview study of 22 immigrant Latinx caregivers found that a majority (72%) attributed communication deficits in ASD to traumatic events, fears, or sadness during pregnancy (Ijalba, 2016).

Studies of Latinx parents receiving ASD services report some awareness of the genetic underpinnings of ASD, alongside misconceptions about etiology. In a qualitative interview study of 25 Latinx parents, most attributed their child's ASD to genetics or a family history of disabilities (Cohen & Miguel, 2018); several also reported the (erroneous) belief that ASD "skips a generation." Quantitative studies have found that Latinx parents are less likely to endorse genetic causes of ASD compared to White parents (Zuckerman, Lindly & Sinche, 2016; McLeod & DiSabatino, 2019). In a survey of 197 parents of children with ASD, 54% of Latinx parents endorsed the belief that vaccines cause autism, compared to 37% of White parents (Bazzano et al., 2012). Latinx parents are also likely to attribute symptoms to poor parenting or negative family relationships (DuBay, Watson, & Zhang, 2018; Salkas, Magaña, Marques, & Mirza, 2016; Zuckerman, Sinche, Cobian et al., 2014; Zuckerman, Sinche, Mejia et al., 2014). These frequent misconceptions about the genetic underpinnings and other causes of ASD, expressed by



families already enrolled in community clinics, suggest that parents are not receiving adequate information from treatment providers.

There is little research examining causal beliefs in Black American communities. Many Black American mothers attribute ASD to vaccinations, and they do so more often than White parents (58% vs 37%, respectively) when controlling for socioeconomic status (SES; Bazzano et al., 2012). However, they are less likely to discontinue or change their child's vaccination schedule after receiving an ASD diagnosis (Bazzano et al., 2012). Black American parents are also more likely to endorse beliefs about post-natal exposure causes of ASD (Zuckerman et al., 2016). An unpublished dissertation study on Black American parents' perceptions of ASD ( $n=45$ ) found that most parents endorsed genetic causes (51%), vaccines (42%), and God's will (42%) as primary causes of ASD. Only 29% of Black American parents ranked genetics as the most important aspect (Llorens, 2016).

Beliefs that ASD is a mystery (Zuckerman et al., 2015) or a result of traumatic experiences (Dardennes et al., 2011) are associated with reduced behavioral intervention; thus, better education may increase service utilization. Seeing ASD as a "mystery" can interact in unexpected ways with service use. A study of 305 mothers of children with ASD reported that those who described ASD as a "mystery" used *more* ASD intervention services, regardless of severity, race, ethnicity, or language (Reyes et al., 2018). Few studies have compared causal beliefs about ASD or how these beliefs impact service use across racial groups. Although every family is different, these results suggest that Latinx and Black American families' misconceptions likely contribute to reduced service use.

### **Beliefs about the course of ASD**

Latinx families saw ASD as a temporary condition in several qualitative studies (Ijalba et al. 2016; Lobar et al., 2014; Voelkel et al. 2013; Zuckerman et al., 2014b). Larger quantitative studies reported mixed findings. Reyes and collaborators (2018) studied 305 mothers of children with ASD (English-proficient or limited-English-proficiency Latinx and White mothers). Parents across all groups saw ASD as a lifelong condition, with major consequences for their child, that could be influenced by intervention (Reyes et al., 2018). However, mothers with limited-English-proficiency were more likely to believe that ASD was a “mystery,” and mothers with less education (across groups) were more likely to believe that symptoms were unchangeable. Related research suggests that the belief that ASD is temporary is not related to levels of distress (McLeod et al., 2019; Zuckerman, Lindly, Sinche, & Nicolaidis, 2015). In one recent study, Black American parents reported beliefs that ASD is a chronic disorder and endorsed a moderately high degree of control over their child’s symptoms (Llorens, 2016). However, a survey of 1420 families of children with special needs found that parents of Latinx and Black American children with ASD were more likely than White parents to see the condition as temporary, controlling for ASD severity. Across groups, lower SES was associated with the belief that ASD is a mystery, and lower education was associated with skepticism about the efficacy of treatment (McLeod et al., 2019; Zuckerman et al., 2015). Altogether, these results suggest that race/ethnicity, SES, acculturation, and language proficiency each impact parental beliefs and the likelihood of seeking services.

### **Understanding early signs of ASD**

Knowledge about ASD symptoms and child development influences the starting point of the diagnostic process (DuBay et al., 2018; Ijalba, 2016; Liptak et al., 2008; Longtin & Principne, 2016; Magaña et al., 2013; Ratto, Reznick, & Turner-Brown, 2016; Stahmer et al.,

2019; Zuckerman et al., 2014; Zuckerman et al., 2014b). In a questionnaire study, Latinx mothers of children with ASD ( $n=28$ ) had significantly less knowledge of ASD symptoms, developmental milestones and adaptive skills, compared to White mothers ( $n=28$ ), controlling for maternal education (Ratto et al, 2016). This finding is echoed in multiple qualitative studies (DuBay et al., 2018; Ijalba, 2016; Lopez, Magaña, Xu, & Guzman, 2018; Stahmer et al., 2019; Zuckerman et al., 2014; Zuckerman et al., 2014b). For example, many Latinx mothers were unfamiliar with ASD prior to their child's diagnosis (Ijalba, 2016; Lopez et al., 2018; Zuckerman et al., 2014). Almost all Latinx mothers in another questionnaire study ( $n=96$ ) endorsed a need for more ASD information (Iland, Weiner & Murawski, 2012). Caregivers with limited-English-proficiency ( $n=94$ ) were more likely to endorse inadequate ASD knowledge as a barrier to services, and report fewer therapy hours and more unmet need, when compared to English-proficient Latinx ( $n=95$ ) or non-Latinx White ( $n=163$ ; Zuckerman et al., 2017) caregivers. Latinx parents are often presented with low-quality Spanish language resources (Blanche et al., 2015; Zuckerman et al., 2014b).

In Black American communities, parents report reduced ASD awareness, and misinformation (Burkett et al., 2015; Iadarola, Pérez-Ramos, Smith, & Dozier, 2019; Stahmer et al., 2019), a finding echoed in several unpublished dissertations (Brown, 2018; Davies, 2018; McCoy et al., 2018). Parents also report that others in their communities might be reluctant to learn about ASD (Iadarola et al., 2019). A qualitative study of 24 Black American family members found that families were unaware of similar ASD prevalence across Black American and White communities, or of diagnostic delays and treatment differences between their communities (Burkett, Morris, Manning-Courtney, Anthony, & Shambley-Ebron, 2015). A study of 34 urban Black American parents found that decreased knowledge of evidence-based

interventions was associated with poverty (Longtin et al., 2016). Both Latinx and Black American caregivers express insufficient access to information about ASD resources and services, which results in delayed diagnosis and services (Stahmer et al., 2019).

ASD knowledge is critical for understanding early signs of ASD and accessing services. This knowledge is also influenced by factors interacting with race and ethnicity: acculturation (Colbert, Webber, & Graham, 2017; Voelker et al., 2013), religiosity (Colbert et al., 2017), SES (Colbert et al., 2017; Longtin et al., 2016), social support (Colbert et al., 2017), and English language proficiency (Colbert et al., 2017; Reyes et al., 2018; Zuckerman et al., 2014b; Zuckerman et al., 2017). Lack of ASD knowledge is particularly salient within Latinx and Black American communities, even when parents are already in the healthcare system. It is associated with later age of first concern and age of diagnosis (Ratto et al., 2016); further, this presents a barrier to early identification and service use (Blanche et al., 2015; Burkett et al., 2015; Zuckerman et al., 2014; Zuckerman et al., 2017; McCoy, 2018) and reduces parenting confidence (Lopez et al., 2018). Relevant to these findings, healthcare providers indicated that they perceive Latinx and Black American parents and caregivers as less knowledgeable about ASD than White parents (Zuckerman, 2013). Regardless of their accuracy, such perceptions could negatively impact the patient-provider relationship and treatment progress

### **Stigma**

Families of children with ASD experience significant stigma; that is, prejudicial attitudes, negative stereotypes and acts of discrimination targeting a subgroup (Corrigan, 2004). This experience has negative effects on care-seeking behavior (Gray 1993, 2002; Corrigan, 2004; dos Reis et al. 2010; Hatzenbuehler, Phelan, & Link, 2013); it also exacerbates existing healthcare disparities for Black American and Latinx individuals, relative to Whites (Conner, Koeske, &

Brown, 2009; Das, Olfson, Mccurtis, & Weissman, 2006; Nadeem et al., 2007). Latinx and Black American parents of children with ASD are at a greater risk of experiencing stigma due to being a member of a marginalized group *and* having a child with ASD, a phenomenon known as *double disadvantage* (Dowd and Bengtson, 1978). ASD-related stigma may thus have a particularly strong influence on healthcare utilization for these populations (Hatzenbuehler et al., 2013).

Research with Latinx families indicates that stigma is a meaningful concern. Parents report that their communities often perceive disabilities as shameful and experience pressure to conceal their children's atypical behaviors and diagnosis (Zuckerman et al., 2014; Stahmer et al., 2019); family and community members may also question the credibility of the diagnosis (Iadarola et al., 2019; Stahmer et al., 2019). Parents report feeling discomfort in sharing concerns with healthcare providers and community members, fearing that their children will be judged or shunned and that their parenting skills will be questioned (Cohen et al., 2018; Dubay et al., 2018; Iadarola et. al, 2019; Lobar, 2014; Stahmer et al., 2019; Zuckerman et al., 2014). In an ethnographic study, 12 Latinx families reported that they were often deterred from advocating for services by fears of retaliation and judgement from professionals. Investigators also found that those who nonetheless advocated for services despite these fears were often questioned, underestimated, and ultimately denied access to services by school professionals (Angell & Solomon, 2017). Latinx parents report experiencing loneliness and limited support as a result (Stahmer et al., 2019). In a qualitative study with 44 Latinx and 52 White mothers, Latinx mothers reported feelings of guilt about their child's ASD diagnosis, whereas White mothers reported relief, suggesting that stigmatizing messages might be internalized by Latinx parents

(Lopez et al., 2018). Concerns about stigma can deter parents from accessing services and social support (Angell & Solomon, 2017; Idarola et al., 2019; Stahmer et al., 2019).

A quantitative study of stigma in Latinx families found that non-U.S.-born parents, and those with limited English-proficiency, experienced greater stigma than White parents (Zuckerman et al., 2018); stigma was also associated with poverty and greater symptom severity. Greater stigma was related to unmet treatment needs, controlling for the amount and type of treatment, suggesting that stigma has a significant impact on quality of care. Latinx families likely experience more stigma when providers are unprepared to interact with families of marginalized backgrounds, and when language barriers are present. Overall, ASD is highly stigmatized in Latinx communities, especially for lower SES and limited-English-proficiency immigrants (Zuckerman et al. 2018). Taken together, these factors lead to social isolation, unmet treatment needs and parental guilt (Blanche, 2015; Idarola et al., 2019; Ijalba et al. 2016; Zuckerman et al., 2018).

Families of Black American children with ASD also experience significant ASD-related stigma. Parents express a lack of acceptance in their communities (Burkett et al., 2015; Brown, 2018; Lovelace, Tamayo & Robertson et al., 2018; Parks, 2017; Stahmer et al., 2019) and report feeling guilty and blamed for their child's ASD (Burkett, Morris, Anthony, Shambley-Ebron, & Manning-Courtney, 2017; Lovelace et al., 2018; McCoy, 2018). Community members often attribute behavioral symptoms of ASD to a lack of discipline or poor parenting and question the ASD diagnosis; these experiences result in feelings of loneliness and isolation and a reluctance to share the diagnosis (Stahmer et al., 2019). Parents in an unpublished dissertation study reported that individuals with severe ASD are often feared (Brown, 2018). ASD-related stigma is also prevalent among African immigrants; an unpublished dissertation study reported that children

could be abandoned or isolated and receive negative treatment and abuse from people in their communities (Davies, 2018). Denial, shame, and stigma delay treatment and decrease research participation (Dababnah, Shaia, Champion & Nichols, 2018; Davies, 2018; Stahmer et al., 2019). A recent qualitative cross-cultural study suggests that Latinx and Black American parents are more likely to have their parenting style questioned, compared to Korean parents (Stahmer et al., 2019). Overall, research suggests that Latinx and Black American parents experience significant stigma from their communities and the institutions designed to support families of children with ASD. These experiences of stigma contribute to service disparities.

### **Protective factors**

Some aspects of Latinx and Black American cultures serve to protect and buffer families from some of the stresses associated with parenting a child with ASD. While caregivers of children with ASD generally report higher levels of parenting stress, this experience varies by culture. Both Latinx and Black American families describe the caregiver role as *less* burdensome than White American families (Connell & Gibson, 1997). For example, Latinx and Black American mothers reported greater positive contributions of their child's ASD, which in turn related to lower levels of anxiety symptoms (Ekas, Tidman & Timmons, 2019). In a study of 88 White and 20 Latinx mothers of children with ASD, Latinx mothers reported less anger and fatigue, a greater sense of "mastery" of their own lives, and better psychological well-being, despite economic disadvantages (Magaña & Smith, 2006). They also reported greater satisfaction with their child, family cohesion, peace of mind and personal growth. A study with 46 Latinx and 56 White mothers found fewer perceived family problems, and less pessimism about the child's future among Latinx participants (Lopez et al., 2018). Latinx mothers were more likely to report seeing a "silver lining" in adverse circumstances – a phenomenon known as *benefit*

*finding* (Ekas et al., 2016). Notably, however, Latinx parents were more likely to report feeling “upset” about the ASD diagnosis, compared to parents of other races/ethnicities (McLeod et al., 2019).

Studies with Black American families suggest more mixed results. A group of Black American mothers perceived the impact of their child’s ASD symptoms as less negative when compared to White mothers (Bishop, Richler, Cain & Lord, 2007); this finding remained five years later (Carr & Lord, 2013). Black American families reported more stress, and reliance on a greater variety of coping strategies, compared to White families, particularly when they were less acculturated toward the majority culture (Williams, Hartmann, Paulson, Raffaele, & Urbano, 2019). Importantly, parents who perceived a more negative impact of the diagnosis had children who received *more* treatment hours (Carr et al., 2013), suggesting that positive perceptions may reduce motivation to access services. Family cohesiveness, interdependence and caregiving values may help parents find meaning in their responsibilities. While this might reduce the impetus to seek services, a better understanding of these factors would facilitate a more informed approach to service delivery and enhance our understanding of how to better support Latinx and Black American families.

### **The role of religion**

Religion plays an important role in family life (Caplan, 2019; Krok, 2018). On the negative side, religious beliefs are sometimes associated with passive and avoidant behavior (Strug, Mason, & Auerbach, 2009); however, these beliefs can promote better planning, positive reframing and active coping (Umezawa et al., 2012), and they can provide membership in communities. Religious beliefs influence how families cope with, understand, and manage challenges (Dyches et al., 2004). For instance, higher levels of spirituality are associated with



mothers viewing their child with ASD as providing a positive contribution to the family (Ekas et al. 2019). In the case of ASD, Latinx caregivers are more likely to report that their child is a blessing, a test, or a message from God (Estrada & Deris, 2014; Salkas, 2016; Lobar et al., 2014). Latinx caregivers are also more likely to endorse the belief that a child can be cured through divine intervention (Ijalba, 2016). In a phenomenological study (relying primarily on interview and survey methods), most Latinx family members (7 out of 10) endorsed using “faith” as an at-home treatment (Estrada et al., 2014). Faith in God also helps Latinx parents advocate for services (Burke et al., 2019).

Religion also has a strong influence on beliefs, coping strategies and treatment choices in the Black American and African immigrant communities. Black American parents report believing that ASD is God’s will or a blessing (Burkett et al., 2017; Llorens, 2016). Families in these communities tend to pray often and to report a belief that God will lead them (Estrada et al., 2014; William et al., 2019). Religious attributions and coping appear to be more frequent in individuals who endorse subscribing to Black American beliefs and traditions, compared to Black individuals who are more acculturated towards mainstream U.S. culture (William et al., 2019). African immigrants are more likely to believe that ASD is caused by evil spirits or a curse. Engaging in spiritual interventions is also common, though most parents report that non-spiritual interventions are preferred (Davies, 2018). In sum, research indicates that both Latinx and Black families in the U.S. rely heavily on religion to cope with and understand their children’s disability.

### **The role of families**

Latinx and Black American families report that family members play a central role in their experiences of raising a child with a developmental disability. Family-centered values in

Latinx communities are linked to better quality of life among mothers of children with intellectual disability (Cohen et al., 2014), and are correlated with more supportive co-parenting behaviors (Lindsey, 2018). Extended family members of children with ASD may be the first to raise concerns about a child's development; Latinx respondents in a qualitative study believed that the family was uniquely able to understand the child (Lobar, 2014). Latinx parents report relying on other family members for childcare, transportation, and financial support; co-housing is common (Estrada et al., 2014; Stahmer et al., 2019). In one qualitative study, Latinx mothers reported receiving less help from their families relative to White mothers (Lopez et al., 2018); in contrast, in a quantitative study, Latinx and White mothers reported similar levels of emotional bonding within the family and perceptions of family support (Ekas et al., 2016). In Black American communities, family members provide critical emotional, economic, and logistical support (Burkett et al., 2017; Stahmer et al., 2019). Latinx and Black American parents express the importance of involving family in the diagnostic process, as they are often the ones recognizing first signs and recommending evaluation (Stahmer et al., 2019). Clearly, extended family members are a vital source of support for both Black American and Latinx caregivers. At the same time, close-knit family relationships can be problematic. Latinx values of *familismo*, or the central importance of family (Davila, Reifsnider, & Pecina, 2011), may lead families to first seek advice and guidance within the family (Edgerton & Karno, 1971), potentially delaying the diagnostic process. Family members may provide counterproductive advice by advocating firm discipline or a "wait and see" approach (Dubay et al., 2018; Blanche et al., 2015; Ijalba, 2016; Lopez et al., 2018; Stahmer et al., 2019).

A similar pattern is described in Black American families. When families of children with disabilities seek guidance from family, friends and church members, they receive social

support (Burkett et al., 2015; Rogers-Dulan & Blacher, 1995; Stahmer et al., 2019), but this process can delay diagnosis. Black American parents report that family members often deny the existence of the disability, blame them for their child's symptoms, believe children will grow out of it, or suggest that parents turn to faith (Brown, 2018; Lovelace et al., 2018; Pearson & Meadan, 2018; Llorens et al., 2016; Stahmer et al., 2019). Some parents also report feeling abandoned by their extended family members and perceiving a lack of familial support (Brown, 2018; McCoy et al., 2018). Though family support alone does not account for racial and ethnic disparities in service utilization, understanding these values is central to assessing coping and to developing culturally sensitive interventions.

### **Gender Roles**

Research assessing how gender roles impact health care utilization is limited. Latinx cultures are broadly characterized by strong gender roles, in which mothers are most responsible for caregiving and describe motherhood as their primary role (Estrada et al., 2014; Magaña et al., 2006). Such gender roles may contribute to diagnostic delays, if mothers must negotiate the logistics of clinical care alone. In a quantitative study of 33 Latinx families, *machismo*, or adherence to traditional gender roles, was described by mothers as exacerbating stigma, with fathers believing that their child with ASD reflected negatively on them (Zuckerman et al., 2014). Fathers with more 'machismo' were more likely to dismiss their partner's concerns, to be uncooperative with the diagnostic process, and to participate less in childcare. Machismo has been linked to less supportive coparenting behaviors in Latinx communities (Lindsey, 2014). A study of 15 Latinx families reported that fathers were generally less involved and understood less about their child's symptoms (Blanche et al., 2015). A majority (72%) of Latinx mothers in a questionnaire study endorsed needing support to help their spouses accept their child's condition

(Iland et al., 2012). Another study of 46 Latinx caregivers found that female participants reported advocating more assertively on behalf of their child, compared to their more passive husbands (Burke et al., 2019). A study comparing coping styles between Latinx fathers ( $n=43$ ) and mothers ( $n=46$ ) found that mothers reported greater depressive symptoms and greater use of positive and support coping than fathers; however, both mothers and fathers reported similar levels of optimism and **similar reliance upon** avoidant coping (Willis, Timmons, Pruitt, Schneider, Alessandri & Ekas, 2016)

Studies of Black American families also indicate gender differences in rearing responsibilities. Families report concerns about self-sufficiency (Burkett et al., 2017), with mothers more focused on independence in activities of daily living (e.g., dressing, making lunch), and fathers more focused on preventing harm from others and guarding against racism. Parents report sharing the responsibilities of child rearing (Burkett et al., 2017). On the other hand, an unpublished dissertation study suggests that pressure to conform to the expectation that Black women should be strong, independent and able to manage difficulties alone can lead to delays in seeking help (Parks, 2017).

### **Patient-Provider Relationship**

Latinx and Black American communities value open and frequent communication, and close personal relationships with their healthcare providers (HCP) that are grounded in respect, trust, and flexibility. Latinx parents often prefer to include extended family members in their child's therapies, and express greater interest in group interventions with other parents (DuBay et al., 2018). Black American parents express a desire for providers to show respect for their values, beliefs and parenting abilities, and want providers to integrate the family's child-rearing practices into treatment plans and to adapt therapies for home use (Burkett et al., 2015).

While ASD healthcare disparities among Latinx and Black Americans may reflect the impact of factors like stigma and a lack of ASD knowledge on service utilization, consistent differences in the quality of the patient-provider relationship, and in access to high-quality, culturally competent services relative to Whites may also play a key role (Magaña et al., 2012; Parish et al., 2012). The quality of the relationship with HCPs impacts a family's engagement in treatment and the time of diagnosis (Parish et al., 2012). Unfortunately, members of Latinx and Black American communities report more unsatisfying and difficult experiences with their HCPs, in part because HCPs frequently underestimate non-White parents' education and knowledge (Angell & Solomon, 2017; Stahmer et al., 2019; Zuckerman et al., 2014; Gourdine, Baffour & Teasley, 2011). Latinx and Black American parents are often met with providers who suggest a "wait and see" approach and normalize their behavioral concerns; Spanish-speaking and Black American caregivers often understand this to be a reaction to their race or culture and feel invalidated (Stahmer et al., 2019). Families who describe their HCP as "dismissive" are more likely to have delays in diagnosis (Stahmer et al., 2019; Zuckerman et al., 2014). Parents receive confusing and conflicting recommendations, and many also experience unprofessional HCP behavior (DuBay et al., 2018). Parents with limited-English-proficiency are more likely to endorse distrust in the HCP as a barrier to service use (Zuckerman et al., 2017); to report receiving conflicting information that is not explained clearly (Stahmer et al., 2019); and to describe feeling discriminated against by professionals for not speaking English (Burke et al., 2019). They also grapple with limited Spanish-language information and services (Blanche et al., 2015; DuBay et al., 2018; Iadarola, 2019; Stahmer et al., 2019; Zuckerman et al., 2014). Even when materials are available in Spanish, the information quality is often poor, inaccurately translated, or filled with medical jargon (Zuckerman et al., 2014b).

Furthermore, many parents are advised by HCPs to speak only English with their children (Ijalba et al., 2016); this advice is misguided, given strong evidence that bilingual children with ASD fare as well as monolingual children and may benefit from broader inclusion of family members in caregiving (Hambly & Fombonne, 2012; Ohashi et al., 2012; Petersen, Marinova-Todd, & Mirenda, 2012; Dai, Burke, Naigles, Eigsti & Fein, 2018). Parents also describe provider confusion around what language their child should speak (Stahmer et al., 2019). Latinx parents report that they receive less information about ASD, compared to White parents (Iadarola, 2019). Black American parents report similarly difficult experiences with HCPs who ignore or disregard family members and their concerns (Burkett et al., 2015; Dababnah et al., 2018; Llorens, 2016; Lovelace et al., 2018; Stahmer et al., 2019). They report that HCPs lack cultural knowledge, and implicitly criticize or question child-rearing practices and competence (Burkett et al., 2015). Parents describe receiving fewer services, of lesser quality, and having to advocate for services that are routinely offered to others (Brown, 2018). Of 22 Black American mothers, nearly all ( $n=20$ ) reported that their HCP ignored their initial concerns and did not provide referrals for ASD screening services (Dababnah et al., 2018). Incidents of racism and microaggressions by providers are often described (Dababnah et al., 2018; Gourdine et al., 2011; Lovelace et al., 2018). Black children's health records are often not written in a family-centered manner, which causes parents to feel judged and misrepresented (Angell & Salomon, 2014). For example, a report might describe a mother as "unemployed" or, in a more family-centered fashion, as a "full-time homemaker;" the latter might more effectively portray family members as they see themselves. Distrust of medical professionals impacts how Black American parents seek services (McCoy et al., 2018).

In general, parents of Latinx and Black American children with ASD receive lower-quality healthcare (Magaña et al., 2012; Parish et al., 2012). Clinicians are less likely to recognize the signs and symptoms of ASD in Latinx children (Zuckerman et al., 2013), tend to underestimate the impact of the language of assessment on outcomes (Williams, Atkins, & Soles, 2009), show bias when evaluating vignettes of culturally diverse children with ASD (Begeer, El Bouk, Boussaid, Terwogt, & Koot, 2009), and are less concordant with parent reports of symptoms in younger Black American children (Neuhaus, Beauchaine, Bernier, & Webb, 2018). The most widely-used ASD assessment tools are normed on predominantly White samples, and administration guidelines have little guidance regarding cultural considerations (Harris, Barton, & Albert, 2014). Racial and ethnic disparities are exacerbated by a lack of culturally competent healthcare. To date, the healthcare system has failed to accommodate the needs of a rapidly-growing, racially and ethnically diverse population.

### **Discussion**

Research on ASD in Latinx and Black American communities documents disparities in diagnosis, quality of care, and service utilization. The two largest non-White groups in the United States have long been invisible in ASD literature. Though the literature is growing, we still have much to learn. This review described parental and community perceptions about the causes and course of ASD; ASD knowledge; the experience of stigma; protective factors; and the role of religious, family, and gender values, in Latinx and Black American communities. We also reviewed community-level factors that influence experiences with healthcare professionals. Understanding these factors will allow providers to better respond to the needs of their patients.

Our review yields several tentative findings. First, these populations struggle with relatively limited knowledge about ASD. They are less likely to be familiar with the “red flags”

of ASD, and more likely to believe that ASD is caused by emotional trauma, ineffective parenting practices, or vaccines. They are also more likely to believe that ASD is a temporary condition. Such beliefs can lead to delays in diagnosis and intervention and increased stigma. More high-quality qualitative research is needed to substantiate these findings, as well as quantitative research that captures the magnitude of the impact of these factors on service use. However, the current findings indicate that more targeted education efforts might lead to meaningful changes in time of diagnosis and ultimately engender improved long-term outcomes.

Potentially more difficult to remediate are the findings that Latinx and Black American families struggle with high levels of ASD-related stigma in their communities. Communities tend to perceive disabilities as shameful; parents experience pressure to hide children who are atypical, and fear judgement of their parenting. Again, stigma contributes to delays in diagnosis and accessing services, is associated with unmet treatment needs, exacerbates social isolation and self-blame among parents, and decreases research participation. While Latinx and Black American communities likely struggle with higher levels of ASD-related stigma relative to Whites, only one study to date has directly compared stigma levels between Latinx and White families (Zuckerman et al., 2018), and there is no research comparing Black American and White families. Additional comparative studies are needed.

Although reduced knowledge and ASD-related stigma exacerbate healthcare disparities, there are important community-specific protective factors. Latinx and Black American families may rely on family members and religious beliefs more than their White peers. Relatedly, parents in these communities tend to report fewer negative impacts of having a child with ASD. Family and religiosity are vital sources of support. Understanding these cultural values is



important to promote effective coping strategies. Increasing access to useful information within these communities can help counterbalance diagnostic delays related to waiting for family input.

Culturally-specific gender roles can either support mothers in the caregiving process or increase their burden. Latinx mothers worry that their male partners feel shame about their child's ASD, dismiss their concerns, struggle to accept the diagnosis, and are less involved in caretaking, all of which increase maternal burden. In Black American families, mothers and fathers appear to prioritize distinct goals related to their respective gender norms (i.e., promoting independence versus preventing harm), and couples may share caregiving tasks equitably. Interpretations of these findings should be made with caution; the body of research directly assessing the impact of gender roles on caregiving among Latinx and Black American parents of children with ASD is limited by its small size and reliance upon maternal perspectives. More studies – particularly those including perspectives of fathers and other male caregivers – are needed to draw more definite conclusions.

In their relationships with healthcare providers (HCPs), Latinx and Black American families desire close and trusting relationships, direct communication, and having their values respected. Unfortunately, these expectations often go unmet, and Latinx and Black Americans experience lower healthcare quality (Magaña et al., 2012; Parish et al., 2012). All too often, HCPs dismiss parents' concerns, underestimate their knowledge, engage in racial and ethnic microaggressions, and they fail to understand and respect cultural values and rearing practices. They also struggle to recognize signs of ASD in non-White children, and account for bilingual or non-fluent language status during assessments. Families report inadequate access to Spanish-language information and Spanish-speaking providers. There are few culturally-appropriate

assessments. These factors all increase healthcare disparities, but could be addressed, at least in part, by education that targets healthcare providers.

There is little research examining how ASD-related stigma, knowledge, and patient-provider relationships contribute to racial and ethnic healthcare disparities. Existing quantitative research is limited by small sample sizes and an under-characterization of study samples in terms of race, ethnicity, and other sociodemographic and cultural characteristics; this limitation is particularly salient because, as reviewed here, immigration status, acculturation, language, SES, and religious beliefs interact with race and ethnicity. Existing qualitative research utilizes well-characterized samples, but often lacks in-depth exploration of how race, ethnicity, and other sociodemographic correlates of ASD disparities – namely SES and parent education level – interact to uniquely impact ASD disparities within Latinx and Black American communities. The specificity of sample characteristics required for strong qualitative research, **while informative about similar groups**, also limits the extent to which results can be generalized to the **general population. As a whole, the available literature – including the research reviewed here – often misses important sociocultural nuances within broader categories of race and ethnicity, such as within-group differences among Blacks (e.g. Black Americans, Jamaican Americans, and Nigerian Americans) and Latinx (e.g., Mexicans, Cubans, and Puerto Ricans) communities. Furthermore, many studies treat Latinx and Black populations as mutually exclusive, without capturing those individuals who share both identities. This obscures the unique impact that race and ethnicity have on Black and Latinx individuals and their access to ASD services. The best practice for future research is to describe the detailed and complex racial, ethnic, and sociocultural backgrounds of Latinx and Black participants. Doing so will increase our understanding of and ability to address how these nuances impact access to ASD services.**

One of the biggest limitations of this research is that Black American communities are underrepresented; only 40% of the published studies in this review include Black Americans, and the results of these studies are not widely generalizable. We cannot hope for better outcomes without a more comprehensive understanding of the current limitations faced by Black American families in need of ASD treatment services. Furthermore, the research does not include families who are *not* receiving services; obviously, these families are the most difficult to recruit and engage in research, but only by understanding their concerns and needs can we hope to increase their engagement. Creative approaches are needed to reach these families at home and in their communities.

**Next steps.** This review of the existing literature, along with our own clinical experiences, suggests several practical strategies that could reduce current inequities. First and foremost, researchers and clinicians alike must acknowledge and remain mindful of the profound role that racial and ethnic biases play in both ASD research and clinical practice. It is vital to recognize the nuanced nature of race, ethnicity, and culture when interpreting the results of research and making treatment recommendations. A failure to do so could lead to the infliction of unintended harm on already vulnerable populations. Second, we must reduce language barriers. Latinx patients will be better served if intervention services recruit Spanish-speaking individuals with the relevant cultural background to deliver interventions (Magaña, Lopez, & Machalicek, 2017). Interpreters should be fluent in the client's language and familiar with their specific culture since language use (e.g., terminology, pragmatics, meaning) varies across Latinx cultures; see Hadziabdic & Hielm (2013) for practical guidance on the use of interpreters in healthcare settings. Written materials such as pamphlets, questionnaires, etc., should be reviewed by a community member to ensure that the language is clear and appropriate (Lajonchere et al.,

2016). HCPs should consider identifying or forming Spanish-speaking support groups to serve Latinx families (Dubay et al., 2018). Recruiting more Spanish-speaking individuals to medical school and other healthcare professions will surely also help to address this challenge.

We can also work to reduce some of the structural barriers that often limit Latinx's and Black Americans' access to ASD diagnostic and treatment services. For example, providers can offer extended hours for caregivers who cannot afford to take a day off from work for an appointment; help them arrange transportation or childcare; or provide web- or community-based services (i.e., telehealth and mobile screenings; Nowell et al., 2015); one outcome of the 2020 COVID-19 pandemic has been increased availability of telehealth services. Furthermore, community-based clinics could partner with local sponsors and public health organizations to offer families access to assessment, consultations and service recommendations; the Rhode Island Consortium for Autism Research and Treatment (RI-CART) is a working model, bringing together families and people with ASD, researchers, clinicians, educators, and local agencies, with a mission of education, improving access to intervention and support services, and promoting research (Gerber, Morrow, Sheinkopf & Anders, 2014). Home-based intervention or parent-training might be especially appropriate for this population (Dubay et al., 2018).

Because family ties are critical in both Latinx and Black American communities, including extended family members in treatment can increase intervention efficacy (Buzhardt, Rusinko, Heitzman- Powell, Trevino- Maack, & McGrath, 2016; Magaña, Li, Miranda, & Paradiso de Sayu, 2015). This approach will also reduce stigma by increasing awareness and knowledge of the disorder in all family members. For example, providers could encourage parents to bring influential extended family members to appointments. Doing so could enhance family-provider relationships and allow for more comprehensive clinical observation. HCPs

should explicitly ask about parenting values and incorporate these values into treatment planning (Zayas and Solari, 1994). These values may be at odds with evidence-based intervention approaches; clinicians must engage in shared decision-making and partnership with families to determine appropriate treatment options. Stiggebout and collaborators (2012) present some useful strategies on how to engage families in such partnerships.

Providers should also aim to understand their clients' cultural backgrounds, identities, and belief systems. Explicitly asking about these attributes, for example by using the semi-structured Cultural Formulation Interview (Lewis-Fernández, Aggarwal, Hinton, Hinton, & Kirmayer, L. J., 2016), can aid this process. Being respectful and aware of religious beliefs (Johnson & Van Hecke, 2015) and cultural sayings (Magaña et al., 2017) can increase the connection between HCPs and their patients. Although not all families are devout, HCPs should be open to explicit conversations about spiritual beliefs (Salkas et al., 2016). With regards to gender roles, HCPs should probe how each family negotiates caretaking responsibilities, helping families to build on each parent's strengths. One of the simplest and most important strategies HCPs can use is to invest time in fostering a trusting relationship with parents. This is especially important when working with Latinx and Black American families because of historical mistrust between these populations and the medical community.

The scientific and clinical communities should collaborate to reduce the knowledge gap in Latinx and Black American families by helping parents understand the symptoms and causes of ASD, informing them about services, minimizing the stigma of ASD, and clarifying common misconceptions, like the belief that vaccines, bad parenting, or trauma cause ASD. Educational material should be free of jargon and include photos of people from non-White groups (Lajonchere et al., 2016). Providing video recordings of materials will make them more

accessible to individuals with lower literacy (Durkin et al., 2010; Zuckerman et al., 2014b). Latinx community members have also suggested targeted radio and TV campaigns that provide concrete and straightforward information (Zuckerman et al., 2014). Literature can be distributed by community organizations, and announcements regarding services can be broadcast in community spaces. Given the link between low SES and ASD knowledge, information would be particularly impactful when provided by organizations that serve low-income families.

Researchers and HCPs should also consider partnerships between existing clinics and community gatekeepers (e.g., elders, pastors, deacons, etc.) or organizations; this will help expand their own cultural knowledge, gain trust within the communities they serve, and promote ASD awareness (Johnson & Van Hecke, 2015; Moody et al., 2019). For example, one pilot study successfully trained religious leaders to use culturally appropriate materials (e.g., videos of Black American children with ASD symptoms, integrating religious scriptures into the materials) to recognize early signs of ASD and to talk to families about services (Johnson & Van Hecke, 2015). Programs such as the Appreciative Inquiry/Bootcamp Translation program utilize a community-based participatory research framework (Israel et al., 2008) to engage community members and develop practical actions to reduce ASD disparities (Moody et al., 2019); this approach is promising though clearly more research is needed. Stronger relationships with cultural leaders will contribute to greater understanding of the community's cultural context (Moodley & Sutherland, 2010).

One final strategy for reducing health-care disparities is for clinicians to utilize validated autism screeners, such as the M-CHAT-R and the RITA-T, which have demonstrable diagnostic efficacy across racial and ethnic backgrounds (Choueiri & Wagner, 2015; Herlihy et al, 2014). Since non-White and lower-income families receive evaluations less frequently, screeners should

be administered at opportune moments rather than at specific milestones or ages (Adamson, Ben-Shlomo, Chaturvedi, Donovan, 2003). Culturally appropriate assessment norms and cultural considerations should be used when available; efforts to improve these cultural components are urgently needed. This approach will minimize bias in assessment.

Reducing ASD healthcare disparities requires a multi-faceted response from both HCPs and the scientific community. Providers should take a more holistic and culturally sensitive approach to care and ensure that they develop trusting relationships with families. Universal screening is also needed. Researchers must include more non-White participants in their studies and actively study how socio-demographic factors like race and ethnicity influence service use and outcomes. It is essential that professionals in the field recognize and consider the systemic and socio-cultural barriers that decrease Latinx and Black American access to ASD services. This awareness will help clinicians and scientists take deliberate action to reduce barriers and improve the quality of healthcare for the largest proportion of families affected by ASD.

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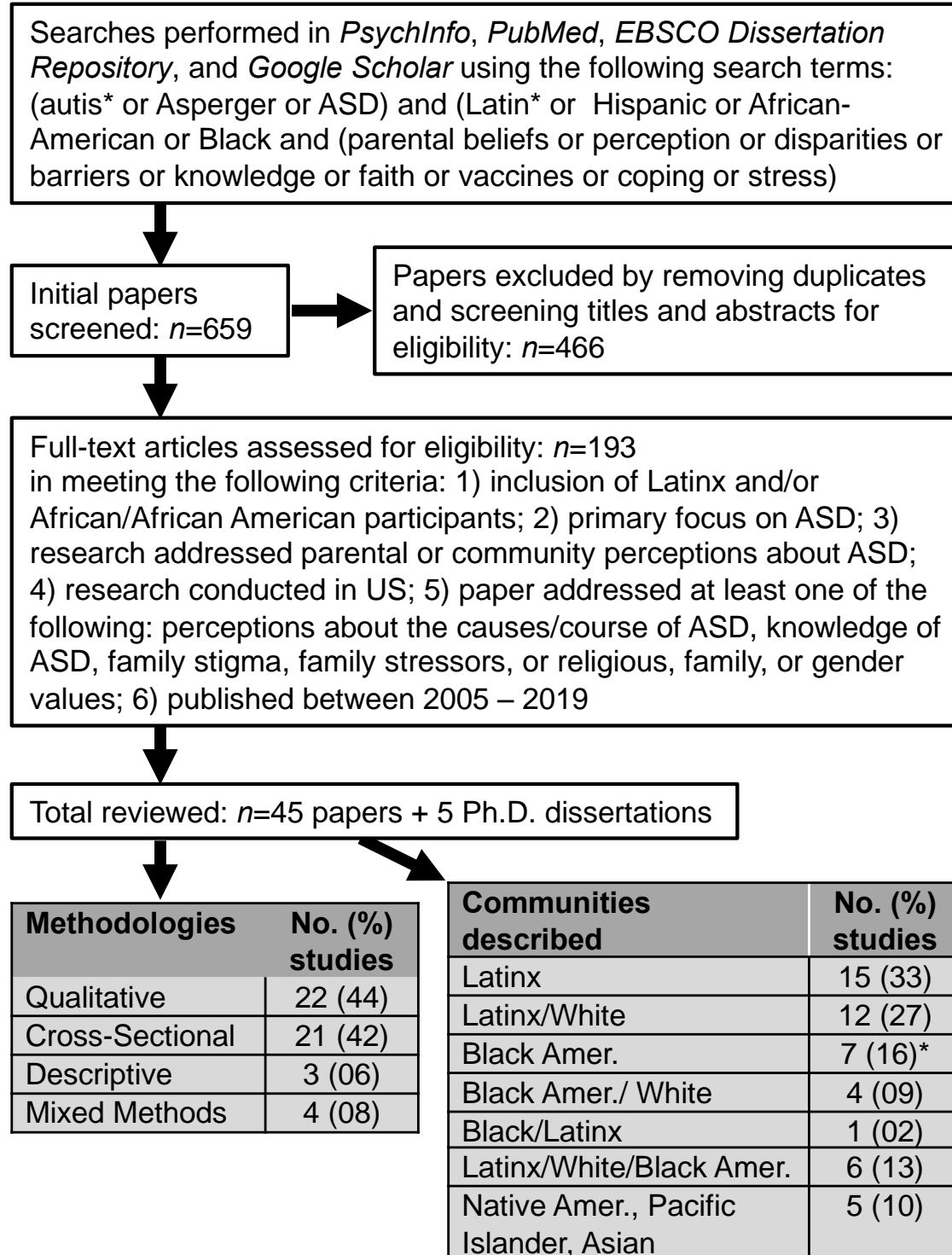
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Figure 1. Scoping review procedure.



Note: \*Excludes five unpublished dissertations described in this review.

Table 1. Characteristics of included studies, ordered by Method and Quality rating.

Method	Populations	N (ordered by Population)	Quality rating	Reference
Cross-sectional	Latinx	67	Good	Colbert et al., 2017
Cross-sectional	Black Amer, Latinx, White	682, 665, 3762	Good	Magaña et al., 2012
Cross-sectional	Latinx, White	48, 56	Good	Magaña et al., 2013
Cross-sectional	Black Amer, Asian, Native Amer/Hawaiian, White	2759	Good	Neuhaus et al., 2018
Cross-sectional	Latinx, White	665, 3762	Good	Parish et al., 2012
Cross-sectional	Latinx, White	160, 145	Good	Reyes et al., 2018
Cross-sectional	Black Amer, White	51, 52	Good	Williams et al., 2019
Cross-sectional	Black Amer, White	30, 80	Moderate	Bishop et al., 2007
Cross-sectional	Latinx, White	73, 44	Moderate	Ekas et al., 2016
Cross-sectional	Black Amer, Latinx, Asian/Pacific Islander, Multiracial, White	2, 10, 1, 4, 56	Moderate	Ekas et al., 2019
Cross-sectional	Black Amer	34	Moderate	Longtin et al., 2016
Cross-sectional	Latinx, White	46, 56	Moderate	Lopez & Magaña, 2018
Cross-sectional	Black Amer, Latinx, White, Other	89, 118, 1056, 145	Moderate	McLeod et al., 2019
Cross-sectional	Black Amer, Latinx, White, Other	89, 118, 1056, 145	Moderate	Zuckerman et al., 2015
Cross-sectional	Black Amer, Latinx, White	26, 52, 91	Lesser	Bazzano et al., 2012
Cross-Sectional	Black Amer, White	17, 68	Lesser	Carr et al., 2013
Cross-sectional	Latinx, White	28, 28	Lesser	Ratto et al., 2016
Cross-sectional	Latinx	169	Lesser	Voelkel et al., 2013
Descriptive	Latinx	267	Good	Zuckerman et al., 2013
Descriptive	Latinx	96	Moderate	Iland et al., 2012
Descriptive	Latinx (1 White, 1 Asian)	29	Moderate	Williams et al., 2009
Mixed Methods	Latinx	25	Good	Cohen et al., 2018
Mixed Methods	Latinx, White	28, 27	Good	Dubay et al., 2018
Mixed Methods	Black Amer	17, 68 (Quantitative); 6 (Qualitative)	Moderate	Llorens, 2018

Mixed Methods	Latinx, White	15	Moderate	Magaña et al., 2006
Qualitative	Black Amer	Caregivers: 11; and 6 Cultural Brokers	Good	Brown, 2018
Qualitative	Latinx	24	Good	Burke et al., 2019
Qualitative	Black Amer	Caregivers: 24; and 28 Healthcare Providers	Good	Burkett et al., 2015
Qualitative	Black Amer	24	Good	Burkett et al., 2017
Qualitative	Black Amer	22	Good	Dababnah et al., 2018
Qualitative	African immigrants	29	Good	Davies, 2019
Qualitative	Black Amer, Latinx, Hawaiian/Pacific Islander, Multi, White	4, 10, 1, 1, 5 (total <i>n</i> =17)	Good	Iadarola et al., 2019
Qualitative	Latinx	0	Good	Ijalba, 2016
Qualitative	Latinx, White	44, 52	Good	Lopez et al., 2018
Qualitative	Black Amer	13	Good	McCoy, 2018
Qualitative	Black Amer, Latinx, Korean	Caregivers: 18, 26, 14; and 55 Healthcare Providers	Good	Stahmer et al., 2019
Qualitative	Latinx	30	Good	Zuckerman et al., 2014b
Qualitative	Black Amer	14	Moderate	Angell et al., 2014
Qualitative	Latinx	12	Moderate	Angell et al., 2017
Qualitative	Latinx	15	Moderate	Blanche et al., 2015
Qualitative	Latinx	14	Moderate	Lobar, 2014
Qualitative	Black Amer	Caregivers: 20; and 2 Healthcare Providers	Moderate	Parks, 2017
Qualitative	Latinx	34	Moderate	Salkas et al., 2016
Qualitative	Latinx	33	Moderate	Zuckerman et al., 2014
Qualitative	Latinx	10	Lesser	Estrada et al., 2014
Qualitative	Black Amer	3	Lesser	Lovelace et al., 2018
Qualitative	Black Amer	16	Lesser	Pearson et al., 2018