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## A Scoping Review of Health Disparities in Autism Spectrum Disorder

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### Abstract

Individuals with autism spectrum disorder (ASD) experience increased morbidity and decreased life expectancy compared to the general population, and these disparities are likely exacerbated for those individuals who are otherwise disadvantaged. We conducted a review to ascertain what is known about health and health system quality (e.g., high quality care delivery, adequate care access) disparities in ASD. Nine studies met final inclusion criteria. Seven studies identified racial disparities in access to general medical services for children with ASD. No studies examined disparities in health outcomes or included older adults. We present a model of health disparities (Fundamental Causes Model) that guides future research. Additional work should examine health disparities, and their causal pathways, in ASD, particularly for older adults.

### Keywords

health; morbidity; mortality; costs; disparities; race; ethnicity; women; geographic; ASD

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Health status and life expectancy vary across the population (Hill et al. 2015), and emerging evidence suggests that people with autism spectrum disorder (ASD) experience heightened morbidity and early mortality compared to those without ASD (Croen et al. 2015; Hirvikoski et al. 2016; Cashin et al. in press). Well-documented disparities in access to diagnostic and early intervention services for ASD (Ennis-Cole et al. 2013; Magaña et al. 2013; Mandell et al. 2007) suggest that individuals with ASD who are otherwise disadvantaged by society—including those who experience disadvantage related to their race, ethnicity, culture, socioeconomic status, environment, geography, sex, or gender

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identity—may experience even greater disparities in health status and life expectancy. As the population of individuals with ASD increases and people on the autism spectrum are more fully included in their communities, better understanding the health status of individuals with ASD, and disparities that may affect health, is of paramount importance for developing physical health promotion and disease prevention efforts that serve the needs of the diverse population of individuals with ASD.

We define health disparities in this paper as the “biological, behavioral, sociocultural, and environmental factors that influence population-level health differences” (Hill et al. 2015). Although health disparities are present across the life span, Link and Phelan’s (1995) Fundamental Causes Model of contextual health disparities suggests that health disparities are particularly pertinent to understanding the emergence of adverse health outcomes because health disparities determine the extent to which individuals can potentially avoid risk. Recently, Hill and colleagues (2015) developed a health disparities framework (Figure 1; Fundamental Causes Model) whereby fundamental factors that lead to disadvantage—including race, ethnicity, culture, socioeconomic status, environment, geography, sex, and gender identity—should be examined at the environmental, sociocultural, behavioral, and biological level in order to identify malleable targets for intervention to reduce disparities and improve outcomes. In the general population, disadvantage is tightly linked to disparities, including lower life expectancy, worse health outcomes, and poorer health care access (Link and Phelan 1995; Hill et al. 2015). Important to the study of health disparities in ASD, health disparities related to disability status (i.e., ASD) may combine with other disadvantaging factors to influence health and health system quality—including high quality care delivery and adequate care access—through causal pathways at the environmental, sociocultural, behavioral, or biological level. Thus, while having ASD may represent a health disparity in and of itself, leading frameworks of health disparities suggest that individuals with ASD who are otherwise disadvantaged may experience further heightened risk for adverse health outcomes compared *both* to the general population *and* to individuals with ASD who are not members of groups that traditionally experience disadvantage.

Consistent with ASD-related disparities, co-occurring medical conditions in children with ASD are well-documented, and emerging evidence suggests that adults with ASD have higher rates of adverse physical health outcomes. In children, co-occurring diagnoses of epilepsy (Spence and Schneider 2009), gastrointestinal disorders (Nikolov et al. 2009), disrupted sleep (Cortesi et al. 2010), and feeding issues (Romero et al. 2016) are common. There is also evidence for shared etiology between ASD and other developmental disorders, including Fragile X, Tuberous Sclerosis, and other single gene mutations, genetic syndromes, chromosomal abnormalities, and de novo copy mutations (Bolton 2009). In adults, a recent review found evidence for high rates of cardiovascular problems and mental health conditions (Cashin et al. in press), and studies have additionally identified high rates of early parkinsonism (Starkstein et al. 2015). Individuals with ASD also have a life expectancy that is between 20 and 36 years shorter than the general population (Hirvikoski et al. 2016; Guan and Li 2017). Heightened adverse physical health outcomes in ASD may be partially explained by known health risk factors, including poor eating habits (Ho et al. 1997), obesity (Ho et al. 1997; Croen et al. 2015), limited physical activity (Ho et al. 1997), long-term psychotropic medication use (Esbensen et al. 2009) and institutionalization

(Krahn et al. 2006). Biological vulnerability as evidenced by studies that find shortened telomere length (Li et al. 2014), hypothalamic-pituitary-adrenal axis dysfunction (Taylor and Corbett 2014), increased oxidative stress (Chauhan and Chauhan 2006), perturbed proteostasis (Louros and Osterweil 2016), and dysfunctional GABAergic signaling in early development (Pizzarelli and Cherubini 2011) may also play a role. Finally, a recent systematic review found that children with ASD have increased costs and higher health care utilization, yet poorer access to health care and medical homes than children in the general population (Tregnago and Cheak-Zamora 2012). Taken together, this evidence points to the presence of ASD-related health disparities throughout the life course.

Consistent with disparities related to disadvantaging factors, evidence also suggests that children with ASD experience disparities in access to diagnostic and early intervention services for ASD. Race, culture, socioeconomic status, and neighborhood disadvantage play a significant role in ASD diagnosis. While expert diagnosticians may be able to diagnose ASD in children as young as 12 months of age (Landa et al. 2007), ASD is typically diagnosed around four years (Christensen 2016). African American children are diagnosed with ASD at least 1.5 years later (Ennis-Cole et al. 2013) and are more likely to receive another diagnosis before receiving an ASD diagnosis (Mandell et al. 2007) than their European American peers. Children from lower socioeconomic status households (Durkin et al. 2010) and children from neighborhoods with high neighborhood disadvantage (Mazumdar et al. 2013) are also less likely to receive a timely ASD diagnosis. Disparities also exist in the availability of and access to ASD treatment services: children from lower socioeconomic status background receive fewer hours of ASD treatment services (Nguyen et al. 2016), and African American and Latino children experience a lag between diagnosis and treatment and receive fewer ASD treatment services (Ennis-Cole et al. 2013; Magaña et al. 2013). Coupled with likely ASD-related health disparities, evidence for racial, ethnic, and sociocultural disparities in access to services to treat and diagnose ASD in early childhood suggests the possibility of similar sociocultural disparities related to health.

Although the research conducted to date suggests significant ASD-related health disparities, these ASD-related health disparities may be additionally amplified for those individuals with ASD who are otherwise disadvantaged, leading to increased adverse physical health outcomes later in the life course. However, health disparities in ASD have not been systematically examined in the literature. This presents a significant barrier to developing an agenda for practice, policymaking, and research related to health disparities in ASD. Thus, the purpose of this review was to broadly ascertain what is known about health and health system quality (e.g., high quality care delivery, adequate care access) disparities related to race, ethnicity, culture, socioeconomic status, environment, geography, sex, and gender identity.

## Method

We conducted a scoping review to broadly ascertain what is known about health disparities in ASD. In contrast to a systematic review which focuses on assessing quality the evidence for a narrowly defined question, a scoping review assesses an area of literature more broadly regardless of study design or methodological quality in order to examine the extent, nature,

and range of research activity and to identify gaps (Arksey and O'Malley 2005; Levac et al. 2010). We employed the search and selection strategy identified by Arksey and O'Malley (2005) and used PRISMA standards for reporting results (Moher et al. 2009).

We defined health disparities within the National Institute on Aging health disparities research framework to include health and health system quality disparities related to race, ethnicity, culture, socioeconomic status, environment, geography, sex, or gender identity (Hill et al. 2015). Because other reviews have identified health and health system quality disparities related to disability (i.e., between individuals with ASD and controls; Tregnago and Cheak-Zamora 2012; Cashin et al. in press), we excluded studies which exclusively focused on disability-related health disparities from our review. Because our review focused specifically on health, we excluded studies that assessed services for the diagnosis of ASD or supportive services directly related to ASD (i.e., applied behavior analysis, social skills groups, speech therapy) and instead focused on general medical services.

### Identification of Relevant Studies

We systematically searched PubMed, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, and the Sociology Research Database (SocINDEX) databases with the help of a reference librarian who specializes in systematic review methodology. Articles were limited to those published in peer-reviewed journals between January 1980 and May 2017. We comprehensively searched key terms related to ASD, health, and disparities. These key terms were truncated and broadened to enable comprehensive coverage per guidelines of scoping review methodologies (Arksey and O'Malley 2005; Levac et al. 2010). ASD was broadened to also include MeSH terms for autism, autistic, or Asperger\*. Health was broadened to include keyword searches for medical, prevent\*, disease\*, screen\*, treat\*, or “unmet need”. Disparities was broadened to include keyword searches for disparit\*, race, ethnic\*, African American, Latin\*, Latino, Asian, Pacific Islander, poverty, income, socioeconomic, “inner city,” gender, or sex. In all searches, we excluded articles solely about caregivers or parents. We also hand-search articles published ahead of print in *Journal of Autism and Developmental Disorders*, *Autism*, *Autism Research*, *Journal of Intellectual and Developmental Disability*, *Research in Autism Spectrum Disorders* and scanned the reference lists of identified articles. The first author performed the search with the help of the reference librarian and managed and analyzed search results using EndNote® software.

### Study Selection

After removing duplicates, the first author scanned titles to assess whether studies addressed ASD, physical health, or disparities (i.e., included any of our key terms and/or broadening terms). The first author then scanned abstracts to ensure that abstracts: (1) included participants with ASD; (2) focused on physical health or access to general medical services; and (3) examined disparities related to race, ethnicity, socioeconomic status, gender, and sex identity. Studies that (1) focused solely on services to treat ASD or co-occurring mental health problems with no focus on general medical services or (2) were descriptive or theoretical in nature (i.e., without primary data) were excluded. Articles identified for inclusion at after abstract search were moved to a separate folder in EndNote for full-text

analysis. The first and second author then analyzed full texts to identify a final list of included studies. Any disagreements were resolved by consensus. Because scoping review methodology is iterative, this allowed for adjustment of inclusion criteria to include relevant studies during consensus discussions (Levac et al. 2010).

### Data Extraction and Reporting

After assembling the final list of studies included in this review, the first and second author extracted theoretically and/or methodologically relevant characteristics. Theoretically and/or methodologically relevant characteristics of studies included the data source, the sample, the methodology employed, and the main findings. These characteristics were then analyzed in order to identify themes and gaps in the literature, and to pinpoint implications for future research, practice, and policy (Levac et al. 2010).

## Results

Our search identified 150 unique studies, of which nine were eligible for inclusion in the final review. The study selection process is presented in Figure 2. Studies were identified in PubMed ( $n = 81$ ), PsycInfo ( $n = 61$ ), CINAHL ( $n = 71$ ), and SocINDEX ( $n = 2$ ). One additional study was published online ahead of print and therefore was not identified by our database search. Of the 216 studies identified by this search, 65 (30.1%) were duplicates. The 150 unique studies were published between 1995 and 2017, and 87.3% ( $n = 131$ ) were published after 2010.

Studies were excluded in stages, as detailed in Figure 2. In total, 112 studies were excluded after title scan—primarily because most were not related to health or health system quality disparities in ASD (i.e., were about screening for ASD). Twenty-two additional studies were excluded after abstract scan. At this step, we sought to identify studies that examined disparities in physical health or health care quality related to race, ethnicity, culture, socioeconomic status, environment, geography, sex, or gender identity. Full-text scan of articles excluded an additional 9 studies because studies were: solely about ASD-related disparities ( $n = 6$ ; e.g., differences between individuals with ASD and controls); not about health ( $n = 1$ ; i.e., treatment services for ASD, not physical health); not about ASD ( $n = 1$ ; e.g., about special health care needs); or were review articles ( $n = 1$ ). Our final review included nine studies (Table 1) that focused on health or health system quality disparities in ASD.

The nine included studies (Broder-Fingert et al. 2013; Doshi et al. 2017; Lin and Yu 2015; Liptak et al. 2008; Magaña et al. 2012; Magaña et al. 2015; Parish et al. 2012; Tint et al. 2017; Zhang et al. 2017) shared a number of methodological characteristics. Eight studies were cross-sectional (Broder-Fingert et al. 2013; Lin and Yu 2015; Liptak et al. 2008; Magaña et al. 2012; Magaña et al. 2015; Parish et al. 2012; Tint et al. 2017; Zhang et al. 2017), and one (Doshi et al. 2017) used panel data to estimate a longitudinal effect using a difference-in-difference-in-difference estimation technique. One (Magaña et al. 2015) of the eight cross-sectional studies followed up on a question posed in a previous wave of data collection, although participants were not linked across waves of data collection and data were analyzed cross-sectionally. Most included studies also used the same dataset: five

studies (Doshi et al. 2017; Lin and Yu 2015; Magaña et al. 2012; Magaña et al. 2015; Parish et al. 2012) used data from the National Survey of Children with Special Health Care Needs. Two of the remaining four studies used other secondary datasets (Liptak et al. 2008; Zhang et al. 2017), while one study (Tint et al. 2017) used prospectively collected survey data and another (Broder-Fingert et al. 2013) used data from a hospital research registry. Sample sizes for included studies ranged from 138 to 132,218, and all studies included participants with co-occurring intellectual disabilities. Finally, although our review searched for studies published since 1980, all included studies were published between 2008 and 2017.

All nine studies examined disparities in health care quality, and specifically access to general medical services; none examined disparities in physical health outcomes (i.e., adverse health outcomes). In terms of disparity categories (i.e., racial disparities), seven (Broder-Fingert et al. 2013; Doshi et al. 2017; Liptak et al. 2008; Magaña et al. 2012; Magaña et al. 2015; Parish et al. 2012; Tint et al. 2017) examined disparities in only one category. The studies that we identified examined disparities in access to general medical services related to race ( $n = 7$ ; Broder-Fingert et al. 2013; Doshi et al. 2017; Lin and Yu 2015; Liptak et al. 2008; Magaña et al. 2012; Magaña et al. 2015; Parish et al. 2012), socioeconomic status ( $n = 2$ ; Lin and Yu 2015; Liptak et al. 2008), sex ( $n = 1$ ; Tint et al. 2017), and geography ( $n = 1$ ; Zhang et al. 2017). No studies examined disparities related to ethnicity, culture, or gender identity. Additionally, all but one (Tint et al. 2017) study focused on disparities in childhood, and not adulthood. We have chosen to discuss the identified studies separately for racial disparities, socioeconomic disparities, and other disparities, below.

### Racial Disparities

Seven of the nine included studies identified disparities related to race (Magaña et al. 2012; Parish et al. 2012; Broder-Fingert et al. 2013; Lin and Yu 2015; Magaña et al. 2015; Doshi et al. 2017; Liptak et al. 2008), and six of seven studies found evidence for racial disparities in health care access and quality for African American and Latino children with ASD.

Six studies examined disparities in access to and quality of care in African American and Latino children with ASD. Three of these studies used parent-reported provider interaction quality metrics collected by the National Survey of Children with Special Health Care Needs (Magaña et al. 2012; Magaña et al. 2015; Parish et al. 2012). All three of these studies found that parents of African American (Magaña et al. 2012; Magaña et al. 2015) and/or Latino children (Magaña et al. 2012; Magaña et al. 2015; Parish et al. 2012) with ASD were more likely than parents of White children with ASD to report not having access to a personal doctor or nurse, have a doctor who does not spend enough time with the child, have a doctor who does not listen carefully, have a provider who is not sensitive about family values and customs, have a doctor who does not make parents feel like a partner, or not receive enough information from the doctor. Additional findings using data from the National Survey of Children with Special Healthcare Needs suggest that parents of non-White children are less likely to report receiving coordinated care and having access to family centered care than parents of White children (Doshi et al. 2017). These findings are echoed by earlier findings from Liptak and colleagues (2008) that indicate that parents of African American and Latino children with ASD were more likely to report having a big or moderate problem getting care



from a specialist, not having a personal doctor or nurse, usually or always having difficulty obtaining needed phone advice, never or sometimes getting acute care in a timely fashion, and having not used prescription medication in the past 12 months. Liptak and colleagues (2008) also found that parents of African American children were more likely to report not having a personal doctor or nurse or having not visited a personal doctor for preventive care. Of note, one study (Lin and Yu 2015) identified a disparity in parents reporting getting needed referrals but did not identify other disparities in reported health care access (i.e., access to sick and well care, access to a personal doctor or nurse, access to care coordination, access to family-centered care) among children with ASD for whom English was the second language, the majority of whom were Latino.

In addition to disparities in health care quality and access to general medical services, African American and Latino children with ASD are less likely to access specialist care as measured by provider record. Broder-Fingert et al. (2013) found that Latino children with ASD have lower rates of neurologic and other testing and that African American children with ASD are less likely to use gastroenterologists, nutritionists, neurologists, psychiatrists, and psychologists and less likely to have had studies for gastrointestinal issues.

Notably, these disparities in health care quality and access are relatively stable: included studies indicate that racial disparities are not improved over time (Magaña et al. 2015) or by state mandates to cover ASD services under private insurance (Broder-Fingert et al. 2013).

### **Socioeconomic Disparities**

Two studies examined disparities related to socioeconomic status in addition to disparities related to race (Liptak et al. 2008; Lin and Yu 2015). Both studies that examined socioeconomic disparities found that parents reported poorer access to care for children with ASD from lower socioeconomic status households. More specifically, Lin and Yu (2015) found that parents of lower-income and uninsured children were less likely to report receiving early and continuous access to care, while Liptak et al. (2008) found that parents of lower-income and uninsured children were less likely to report receiving early and continuous access to care.

### **Other Disparities**

Other disparities identified in the literature include disparities related to sex (Tint et al. 2017) and geography (Zhang et al. 2017). Tint et al. (2017) examined clinical needs and health service utilization among girls and women (females) and boys and men (males) with ASD. They found that females were more likely than males with ASD to report (parent-report for girls and boys, self-report for women and men) receiving psychiatric or emergency department services, although females and males did not differ in their reported clinical needs or on health service utilization within other categories, including primary care, neurology, and physiotherapy services. Finally, Zhang et al. (2017) found that children with ASD whose families live in rural areas, and particularly children with ASD with multiple comorbidities, are more likely than children whose families live in urban areas to use emergency department services. Children with ASD whose families live in rural areas were

also more likely to travel to urban settings for specialist and emergency department care because of lack of access to these services in rural areas or at rural hospitals.

## Discussion

Broadly, this review sought to identify what is known about health and health care quality disparities in ASD. While other reviews have established ASD-related health disparities in people with ASD compared to controls (Tregnago and Cheak-Zamora 2012; Cashin et al. in press), we were particularly interested in disparities related to race, ethnicity, culture, socioeconomic status, environment, geography, sex, and gender identity among individuals with ASD. We focused our review in this way based on a theoretical framework (Fundamental Causes Model) and a sizable health disparities literature in other populations that finds that these disadvantaging factors may compound physical health problems for groups—like individuals with ASD—already at risk of receiving poorer quality health care or experiencing adverse physical health outcomes (Link and Phelan 1995; Hill et al. 2015).

In total, we identified nine studies that met inclusion criteria for our scoping review, all of which focused on disparities in health care access and quality and not on health outcomes. Seven of nine studies examined racial disparities, and two of these studies also examined socioeconomic disparities. The remaining two studies examined geographical disparities (e.g., urban/rural) or disparities related to sex. In general, all included studies identified disparities that led to poorer access to or quality of care for individuals with ASD who are disadvantaged because of their race, socioeconomic status, sex, or geography. These findings align with health disparities findings from other populations with developmental disabilities and mental health problems (Ouellette-Kuntz 2005; Chow et al. 2003). The relatively small number of studies identified by our search strategy for review ( $n = 150$ ) and inclusion ( $n = 9$ ), as well as the recent publication dates for included studies (2008–2017) indicates that health disparities in ASD are indeed a recent and emerging area of inquiry.

We employed a leading model of contextual health disparities (Figure 1) in framing our review. The Fundamental Causes Model (Link and Phelan 1995) builds on the concern with the fundamental impact of social conditions and social factors on the emergence of disease that is emphasized in classical models of epidemiology (Susser et al. 1985). More specifically, this model for understanding contextual health disparities emphasizes social conditions and social factors as fundamental to the emergence of disease because they influence access to resources that help individuals avoid risk for disease and/or minimize the consequences of disease after disease occurs (Link and Phelan 1995). Thus, fundamental, disadvantaging factors—including race, ethnicity, culture, socioeconomic status, environment, geography, sex, and gender identity—affect the degree to which individuals can access the resources needed to prevent and manage disease. In order to mitigate health disparities, we need to understand the ways in which disadvantaging factors affect access to resources. This model therefore postulates that the impact of fundamental factors (i.e., ASD status along with race, ethnicity, culture, socioeconomic status, environment, geography, sex, and gender identity) on physical health outcomes (i.e., adverse health outcomes, costs) must be examined through proximal causes of health disparities (i.e., causal pathways, including



health care access) in order to inform prevention and intervention efforts that have the potential to impart meaningful change in health for individuals with ASD.

The articles identified by this review take some of the first steps in exploring associations between fundamental factors and proximal causes by examining differences in health care access between racial, socioeconomic, geographic, and sex groups. However, based on this model, a number of gaps in the literature remain that limit the ability of the current knowledge base to identify treatment targets and inform the development of prevention and intervention programs. These gaps are detailed in Table 2 and discussed below within the context of our health disparities model.

The lack of studies that focus on physical health outcomes is perhaps the most glaring gap in the literature on health disparities in ASD. Traditionally, research on physical health and health disparities views health outcome measures as discrete, measurable metrics or poorer overall physical health such as adverse health outcomes or increased service utilization as measured by health care costs (Brenner et al. 1995). However, none of the studies that we identified examined disparities in physical health outcomes in ASD. It is possible that another major gap in the literature drives this lack of studies on physical health outcomes: no studies focused on aging, and we found only one study that examined physical health disparities in adults with ASD, and this study only included participants up to age 56. The Fundamental Causes Model of health disparities, and the health disparities literature in general, suggests that fundamental factors influence eventual physical health outcomes through a number of proximal causes (Link and Phelan 1995). Importantly, research in the general population suggests that disparities that begin early in life compound over time to influence the emergence and course of disease later in adulthood (Hill et al. 2015). As a disorder, ASD is unique in that the first cohort of individuals diagnosed by Kanner (1943) are now in their 80s, and the large wave of individuals diagnosed with ASD in the late 1990s and early 2000s (Gerhardt and Lainer 2011) has not yet reached middle age. Thus, it is likely that opportunities will emerge for studies of health disparities in middle aged and older adults with ASD as the population of individuals with ASD ages.

The identified studies were also limited in their examination of causal pathways. All identified studies examined disparities in access to or quality of health care, which fall under the environmental level of analysis of proximal causes proposed by Hill and colleagues (2015). However, the environmental level of analysis encompasses a broad spectrum of factors, including health care access and quality, geographical and political factors (i.e., residential segregation, exposure to environmental toxins, structural bias) and socioeconomic factors (i.e., education, income, assets, limited English proficiency). This model also includes analysis at the sociocultural, behavioral, and biological level (Hill et al. 2015). More specifically, the sociocultural level of analysis includes cultural factors (i.e., prejudice, religion, values), social factors (i.e., institutional racism, stress, social mobility), and psychological factors (i.e., stigma, bias, stereotypes) that may moderate the emergence of physical health problems. It also includes behavioral factors, including coping (i.e., stress management, emotion regulation), psychosocial risk and resilience (i.e., social support, control), and health behaviors (i.e., nutrition, physical activity). Finally, it considers biological factors, including physiological indicators (i.e., comorbidities, inflammation, HPA

axis function), genetic stability (i.e., telomere attrition, epigenetic alteration), and cellular function and communication (i.e., mitochondrial dysfunction, intercellular communication). To fully understand the emergence of health disparities in ASD, and to identify malleable treatment targets that have the potential to reduce health disparities, we must investigate proximal causes across all levels. The studies identified in our review only provide cursory information about proximal causes within only a single level of analysis.

Finally and at the most basic level, Link and Phelan's (1995) Fundamental Causes Model postulates that individuals who are disadvantaged by society because of their race, ethnicity, culture, socioeconomic status, environment, geography, sex, or gender identity experience poorer health outcomes through a combination of causal pathways. Although our review identified racial, socioeconomic, geographic, and sex-based disparities, a number of substantive gaps in the research remain related to fundamental factors. Most notably, we did not identify any studies that examined disparities related to culture, environment, or gender identity. We also did not identify studies that examined health disparities for individuals from diverse ethno-religious (e.g., Muslim, Sikh) or ethno-racial/regional (e.g., Asian, Native American, Pacific Islander, Middle Eastern, or Puerto Rican) backgrounds. Thus, the body of research identified by this review only provides very basic information on the impact of fundamental factors on causal pathways given that research has not yet addressed four out of eight key fundamental factors.

The included studies were also limited in their methodology. First, all included studies used cross-sectional data. While one study (Doshi et al. 2017) used an estimation technique (difference-in-difference-in-difference estimation) to estimate a longitudinal effect, it used cross-sectional data. One additional study (Magaña et al. 2015) followed up on a question posed in a previous wave of data collection to examine whether findings had changed but did not employ longitudinal analyses because of limitations of the dataset that did not allow for linking participants across waves of data collection. The remaining seven studies reported only cross-sectional findings. The cross-sectional nature of included studies does not allow for the examination of trajectories of change over time in physical health outcomes or health care quality. Cross-sectional data also cannot be used to examine causal models. Second, data were drawn from only a few sources. More than half of studies ( $n = 5$ ) used data from the Survey of Children with Special Healthcare Needs. The limited nature of data used calls into question the representativeness and generalizability of findings. Finally, no studies used administrative datasets, and data were mostly based on self- or parent-report metrics of health care access or quality. Therefore, findings may be biased by self-report, are limitedly generalizable to the full population, and may not be representative of all disadvantaged groups.

The findings of this review suggest a number of implications and directions for future research on health disparities in ASD. First, the findings of this review suggest the presence of racial health disparities in ASD related to decreased access to and quality of healthcare earlier in life. Future research should investigate these causal pathways in middle aged and older adults with ASD when physical health problems associated with these disparities are likely to emerge. Second, this review found a small amount of evidence for health disparities related to socioeconomic status. However, this evidence is extremely limited, and more

evidence is needed, particularly using large, nationally representative samples before establishing a concrete understanding of how or whether physical health outcomes differ for individuals with ASD from low and high socioeconomic status backgrounds and contexts. Finally, the research on health disparities in ASD should be generally expanded to focus on aging in middle aged and older adults in order to ascertain true health outcomes for this population nearer the end of life.

In conclusion, while the preponderance of evidence suggests that physical health varies widely across the population, and particularly for individuals and groups who are otherwise disadvantaged by society (Hill et al. 2015), we know relatively little about health disparities in ASD. Although evidence of decreased life expectancy (Hirvikoski et al. 2016; Guan and Li 2017) and poorer physical health in adulthood (Croen et al. 2015) in ASD has only recently emerged, this evidence coupled with the rapidly increasing population of adults with ASD (Gerhardt and Lainer 2011) signals the need to better understand physical health, and factors that promote physical health, in ASD. It is likely that people with ASD who are otherwise disadvantaged have poorer physical health and access to health care throughout life, and this in combination with other factors, leads to worse physical health outcomes as individuals with ASD age. While the evidence characterizing physical health in middle age and beyond in ASD is being built, evidence about the impact of health disparities in ASD needs to be concurrently established. These two endeavors in tandem have the potential to lead to the development of interventions and prevention efforts that maximize health and increase quality of life and life expectancy for the growing number of individuals with ASD.

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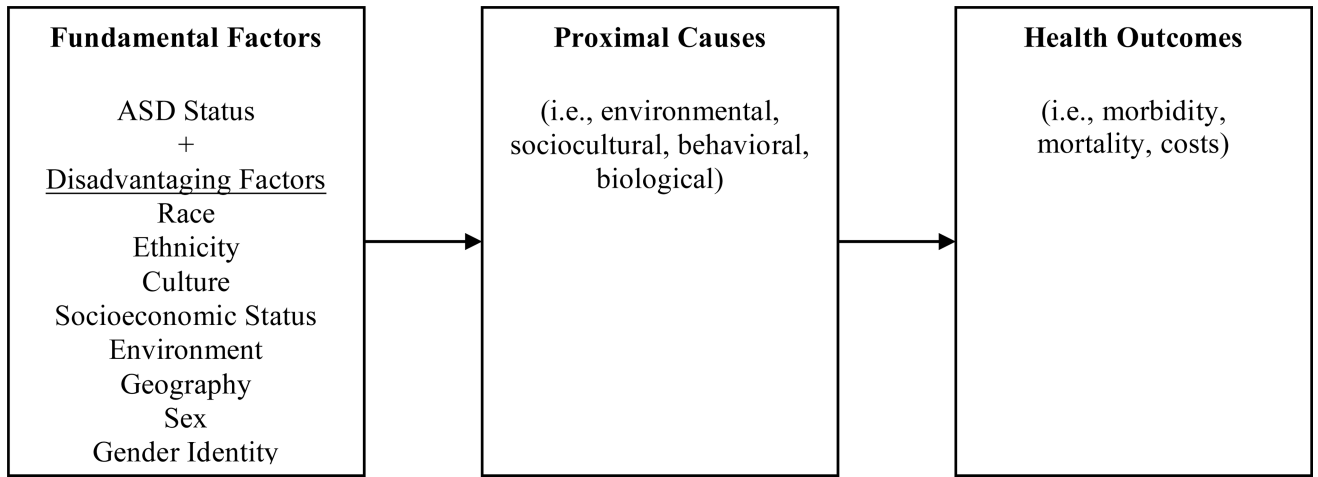
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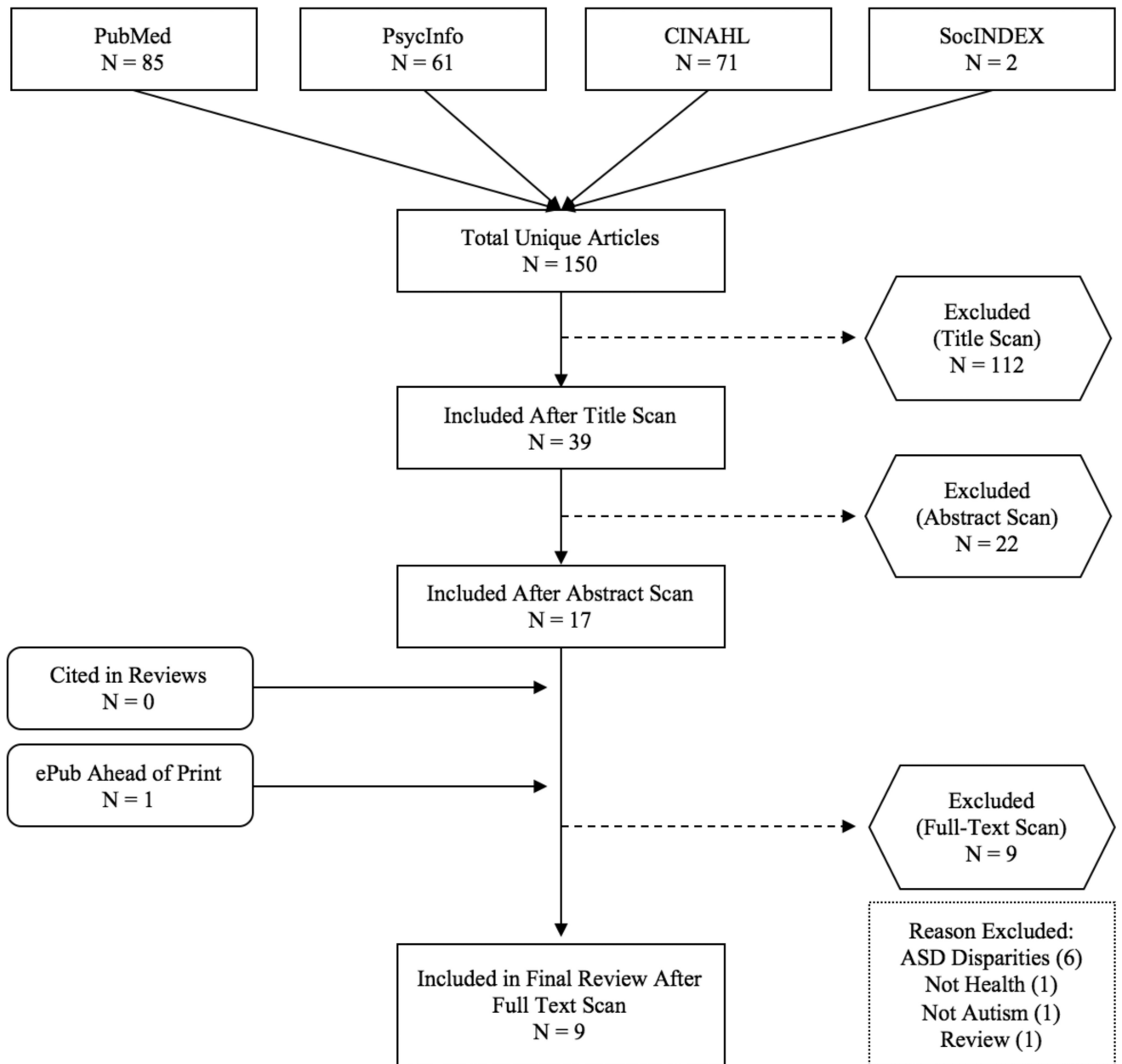
**Figure 1.**  
Fundamental Causes Model of Health Disparities in ASD

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**Figure 2.**  
Flowchart of Article Selection

Table 1

## Characteristics of Included Studies

Study	Data Source	Sample	Description	Main Findings
Broder-Fingert et al. (2013)	Research patient data repository at academic medical center	N=3,615 children with ASD	Cross-sectional; Describe racial and ethnic differences in use of specialty provider visits and procedures in children with ASD.	Non-White children were less likely to use specialty care from GI/nutrition providers, neurology, and psychiatry/psychology and less likely to have had GI studies. Latino children had lower rates of neurologic and other testing.
Doshi et al. (2017)	National Survey of Children with Special Health Care Needs	N=5,178 total children with ASD and race/ethnicity data from 2005/06 and 2009/10 survey waves	Difference-in-difference-in-difference estimation; Test the effect of state mandates for private insurance coverage of ASD on racial and ethnic disparities.	White children with ASD were more likely to receive coordinated care and have access to family-centered care than non-White children; racial disparities were not affected by insurance mandates.
Lin and Yu (2015)	National Survey of Children with Special Health Care Needs	N=138 children with ASD for whom English was not the primary language and N=3,840 children for whom English was the primary language	Cross-sectional; Examined health care access in children with ASD from households in which English was not the primary language.	Children from households where English was not the primary language did not differ from children from households where English was the primary language on measures of health care access. Younger, lower-income, and uninsured children were less likely to have received early and continuous access to care.
Liptak et al. (2008)	National Survey of Children's Health	N=495 children with ASD	Cross-sectional; Examined racial, ethnic, and income-based disparities in access to health care for children with ASD.	Poor, Latino, and/or African American children were less likely to receive care from a specialist, have a personal doctor, be able to obtain phone advice, get acute care in a timely fashion, and use any prescription medicine in the past 12 months than White or higher-income children.
Magaña et al. (2012)	National Survey of Children with Special Health Care Needs	N=5,109 African American, Latino, and White children with ASD/DD	Cross-sectional; Examined racial and ethnic disparities in provider interaction quality for children with ASD and other DD.	There were significant racial and ethnic disparities in five of six provider interaction quality areas. Children with ASD had poorer provider interaction quality in four of six areas. Racial and ethnic disparities are exacerbated among children with ASD in two of six provider interaction quality areas.
Magaña et al. (2015)	National Survey of Children with Special Health Care Needs	N2009/2010=7,053; N2005/2006=5,119 African American, Latino, and White children with ASD/DD	Cross-sectional; Used pooled baseline (2005/2006) and follow-up (2009/2010) dataset examined racial and ethnic disparities in provider interaction quality for children with ASD and other DD. Follow-up to Magaña et al. (2012).	There were significant racial and ethnic disparities in five of six (2005/2006) and four of six (2009/2010) provider interaction quality areas. Racial and ethnic disparities are exacerbated among children with ASD in four of six provider interaction quality areas in 2009/2010. Disparities in provider interaction quality did not improve between baseline and follow-up.
Parish et al. (2012)	National Survey of Children with Special Health Care Needs	N=4,414 Latino, and White children with ASD/DD	Cross-sectional; Examined access to, utilization of, and provider interaction quality for Latino children with ASD and DD.	Latino children experienced disparities in all markers of provider interaction quality of care compared to White children. Three of four indicators of provider interaction quality mediated the association between ethnicity and health care utilization.
Tint et al. (2017)	Survey of service needs of adolescents and adults with ASD in Ontario, Canada	N=61 girls and women and N=223 boys and men with ASD	Cross-sectional; Examined clinical needs and health service utilization among women/girls and men/boys with ASD.	Women and girls with ASD were more likely than men and boys with ASD to receive psychiatric or emergency department services. No significant differences on other service types.
Zhang et al. (2017)	Nationwide Emergency Department Sample (embedded within the	N=132,218 children with ASD from rural (N=20,031) and urban (N=112,187) areas as	Cross-sectional; Examined emergency department utilization for children with ASD, overall, and for children with ASD and	Children with ASD who live in rural areas are more likely to use emergency department (ED) services than children with ASD who live in urban areas. Rural children with ASD and multiple

Study	Data Source	Sample	Description	Main Findings
	Healthcare Cost and Utilization Project from the Agency for Healthcare Research and Quality)	compared to N=36,130,806 children without ASD	multiple comorbidities from both rural and urban areas.	comorbidities were more likely than urban children with ASD and multiple comorbidities to use ED services. Rural families were more likely to travel to urban settings for specialist and ED care because of lack of access in rural areas.

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**Table 2**

## Gaps in the Literature on Health Disparities in ASD

Area	Knowledge Gap
Fundamental Factors	<p><u>Race</u>: Most studies focus on race, but more evidence needed from a wider diversity of populations to draw firm conclusions.</p> <p><u>Ethnicity</u>: No studies examine disparities for individuals from diverse ethno-religious (e.g., Muslim, Sikh) or ethno-racial/regional (e.g., Asian, Native American, Pacific Islander, Middle Eastern, or Puerto Rican) backgrounds; more research is needed.</p> <p><u>Culture</u>: No studies conducted outside of North America; no studies examine the impact of culture on health or health care access within the US; more research is needed.</p> <p><u>Geography</u>: Only one study examined disparities for individuals with ASD living in urban or rural areas; no studies examined other geographical variables; more research is needed.</p> <p><u>Socioeconomic status</u>: Only one study examined the impact of family-level poverty; more research is needed.</p> <p><u>Environment</u>: No studies examined neighborhood poverty; more research is needed.</p> <p><u>Sex</u>: Only one study examined disparities between men and women; more research is needed.</p> <p><u>Gender identity</u>: No studies examined disparities related to gender identity; more research is needed.</p>
Proximal Causes	<p>Studies identified by review examine disparities in access but employ these disparities in analyses as outcome variables.</p> <p>No studies investigate causal pathways at the environmental, sociocultural, behavioral, or biological level; more research is needed.</p>
Health Outcomes	<p>No studies investigated health outcomes within traditional health outcome categories (e.g., adverse health outcomes, costs); more research is needed.</p>