

July 2023

## A Scoping Review of Health Research with Racially/Ethnically Minoritized Adults with Intellectual and Developmental Disabilities

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### Recommended Citation

Williamson, Heather J.; Chico-Jarillo, Tara; Sasse, Samantha; Rennie, Leticia; Etcitty, Jennifer R.; Howe, Carol L.; Lee, Michele Sky; and Armin, Julie S. (2023) "A Scoping Review of Health Research with Racially/Ethnically Minoritized Adults with Intellectual and Developmental Disabilities," *Developmental Disabilities Network Journal*: Vol. 3: Iss. 2, Article 14.

Available at: <https://digitalcommons.usu.edu/ddnj/vol3/iss2/14>

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## Cover Page Footnote

This work was supported by the National Institute of Health under Grant [U54CA143925]; [National Cancer Institute] and under Grant [U54CA143924]; [National Cancer Institute].

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## Plain Language Summary

*Adults with intellectual and developmental disabilities (I/DD) experience worse health compared to their peers without disabilities. We do not know enough about the health of adults with I/DD in the U.S. who are also members of racial or ethnic minoritized groups. This research team reviewed existing health research studies about adults with I/DD from racial or ethnic minoritized groups in the U.S. Most studies found that adults with I/DD from racial or ethnic minoritized groups had different health experiences compared to their peers who were White. This research is important because we need to include people with I/DD who are also part of racial or ethnic minoritized groups in research to improve their health.*

## Abstract

*Living with intersectional identities, having a disability, and being a member of a racial or ethnic minoritized group in the U.S., contributes to marginalization that may result in health disparities and health inequities. The purpose of this scoping review is to describe health research regarding adult racial/ethnic minoritized individuals in the U.S with intellectual and developmental disabilities (I/DD). Eight electronic databases were searched to identify literature on the topic published since 2000. Of the 5,229 records, 35 articles were included in the review. Eligible studies included research conducted in the U.S., published in English, and research focused on adults with I/DD with race and/or ethnicity information. The 35 articles included racial/ethnic minoritized individuals who were Black, Latinx/Hispanic, American Indian, and Asian. Twenty-nine of the 35 articles identified health disparities experienced by adults with I/DD from racial/ethnic minoritized groups. Many health disparities were demonstrated in the articles, where adult racial/ethnic minoritized individuals with I/DD fared worse compared to White adults with I/DD.*

This work was supported by the National Institute of Health (Grant #U54CA143925 and U54CA143924).

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*Additionally, four articles describe differences in health experiences by those from racial or ethnic minoritized backgrounds. Results of this scoping review highlight the need for research that incorporates intentional inclusion of racial/ethnic minoritized people with I/DD and include novel methodologies that allow for the contributions of historically marginalized voices. Future research with an intersectionality approach is recommended to promote equity.*

## Introduction

In this scoping review, we aim to describe the recent health research regarding adult (ages 18 and up) racial/ethnic minoritized people with intellectual and developmental disabilities (I/DD) in the U.S. We specifically focus on health research with adults with I/DD because adulthood among people with I/DD is an area in need of attention. In the U.S., when adults with I/DD “age out” of special education (after age 22), some young adults fall off “the disability cliff,” into “an underfunded and uncoordinated” health care system (Bagenstos, 2015). The siloed nature of disability service systems creates additional challenges in navigating healthcare transition from youth to adult services (Franklin et al., 2019).

### State of Disability in the U.S.

Approximately one in four adults in the U.S. report living with a disability including impairments with vision, hearing, mobility, and cognition (Centers for Disease Control and Prevention [CDC], 2020). Among U.S. adults living with disabilities, prevalence of disability status varies by categories of race and ethnicity. White, Asian American, and Pacific Islander individuals report disability less (24.4%, 16.4%, and 25.4%, respectively) than Black (30.2%), Hispanic/Latinx (31.3%), American Indian/Alaska Native (39.9%), and multiracial (35.8%) adults (CDC, 2020). Previous research indicates a general lack of disability research conducted with a focus on racial and ethnic minoritized groups in the U.S., as the prevailing approach is to focus on disability first and racial identity second (Frederick & Shifrer, 2019).

Intellectual and developmental disabilities are diagnosed before the age of 22. Intellectual disability is characterized by significant limitations in intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical adaptive skills (American Association on Intellectual and Developmental Disabilities, 2023; Krahn & Fox, 2014). The population of individuals with I/DD makes up a small number of individuals in the U.S., but precise estimates have been difficult to achieve (U.S. HHS Administration for Community Living, 2022). Further, this population has experienced a long history of institutionalization and medical mistreatment contributing to additional challenges in surveillance (Krahn et al., 2015; Rembis et al., 2018). Data from the 2015-2016 National Health Interview Survey (NHIS) indicates that 17.8% of children have developmental disabilities and 1.2% experience intellectual disabilities (Zablotsky et al., 2019). Health surveillance among individuals with I/DD in the U.S. is often limited to people who are connected to disability service systems (Havercamp et al., 2019). However, it is estimated that nearly 70% of people with I/DD are not connected to these systems (Bonardi et al., 2019; Braddock et al., 2015). Further, researchers have called for inclusive

disability data collection practices and the inclusion of people with I/DD as co-researchers (McDonald et al., 2016; Mitra, 2013). For example, the NHIS does not sample in some locations where adults with I/DD may live (e.g., nursing homes, group homes; CDC, 2020).

### **Health Disparities Among People with Disabilities**

There is a growing body of evidence documenting health disparities by disability status (Krahn et al., 2015). Health disparities are defined as differences in health outcomes and their determinants between segments of the population by social, demographic, environmental, and geographical attributes (Krahn et al., 2015). These determinants often include race and ethnicity, age, language, sex or gender, socioeconomic status, access to healthcare, and a lack of education, all of which configure the health status of those with disabilities (Krahn et al., 2015). Importantly, rather than race, gender, or social class serving as determinants, bias towards people because of minoritized identities impacts access to resources such as health care, education, or occupation and can lead to poor health outcomes (Paradies et al., 2015). People with disabilities fare worse than their nondisabled counterparts across a broad range of health indicators due to system barriers (Krahn et al., 2015).

Similar to health disparities among people with disabilities, there is a growing body of evidence that suggests the social construction of disability is influenced by one's racial/ethnic identity (Frederick & Shifrer, 2019). The objective of this scoping review is to provide a summary of the existing literature in the area of health research with racially/ethnically minoritized adults with I/DD and identify gaps in the literature to inform a future research agenda.

### **Methods**

A scoping review was completed instead of a systematic review, as the study team wanted to characterize the scope of the research literature rather than evaluating the quality of the research literature (Munn et al., 2018). Specifically, we considered that our topic met at least five of the six indications for conducting a scoping review rather than a systematic review as outlined by Munn et al., namely: (1) to identify as much related literature as possible, (2) to clarify concepts and definitions, (3) to see how previous research has been conducted, (4) to uncover related characteristics/factors, and (5) to expose gaps in current understanding and knowledge. We considered that the sixth indication, to conduct a scoping review as a precursor to conducting a systematic review, would depend on our findings and the more focused questions those findings would generate. Thus, we planned and performed a scoping review using the "PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation" as our reporting guide (Tricco et al., 2018).

### **Eligibility Criteria**

Studies were included if they focused on adults with I/DD and had demographic information about race and/or ethnicity. Only studies in English conducted in the U.S. that were

published after January 1, 2000, were included. Studies were excluded if participants were limited to children or adolescents < 18 years of age or if information about adults 18 years of age could not be separated from the information about children/adolescents; the studies addressed only disabilities other than I/DD; there was no race/ethnicity data; the studies were conducted in countries other than the U.S.; or if no health-related research was conducted or discussed. Reviews, systematic reviews, meta-analyses, case reports, opinion pieces, conference abstracts, dissertations, and nonscholarly publications were also excluded.

## Search Strategy

A medical librarian searched the following databases for publications addressing I/DD and race/ethnicity: Ovid/MEDLINE; Wiley/Cochrane Library; Elsevier/Embase; Elsevier/ Scopus; Clarivate/Web of Science (WOS); EBSCO/ Cumulative Index of Nursing and Allied Health Literature (CINAHL); EBSCO/PsycInfo; and ClinicalTrials.gov. This review included publications from January 1, 2000, through March 26, 2019 (the date the searches were completed). An English language filter was applied to all the searches.

## Study Selection

All records identified through the database searches were exported to the reference management software EndNote Version X9 (Clarivate Analytics, Philadelphia, PA, USA), which was used to document and delete duplicate records. Using EndNote, the medical librarian also prescreened and excluded animal/plant studies, conference abstracts, letters and opinion pieces, articles not available in English, and nonscholarly articles such as newspaper reports.

Two teams of screeners independently screened all titles and abstracts of retrieved references for relevance to our stated purpose. Our team aimed for 100% agreement between the two teams of screeners. Disagreements on inclusion or exclusion were completely resolved by consultation with one of three third reviewers. Using the detailed inclusion/exclusion criteria outlined above, the full texts of those publications selected during the title/abstract phase were then similarly independently screened by two teams. Once again, all disagreements were resolved by consultation with one of the three third reviewers.

## Data Extraction

After screening, two of the reviewers extracted key data points into two separate spreadsheets, which were then compared for concordance. Three additional reviewers (HW, JA, TC-J) resolved disagreements about the data extracted. Data extracted from the articles included the following: lead author, title, publication date, and type; study design; research aims; study inclusion criteria; data type (e.g., existing data source or human subjects research); participant recruitment; sample size; participant demographics (e.g., age, gender race, intellectual and developmental disability diagnosis); intervention (description and setting); data measurement tool; study length; study location; and results.

## Results

We found 8,621 records through database searches (Ovid/MEDLINE 2,037; Cochrane Library 125; Embase 3,571; WOS 1,201; CINAHL 618; PsycInfo 1,064; ClinicalTrials.gov 5). Of the 5,229 publications that remained after duplicates, animal/plant studies, conference abstracts, letters, nonscholarly articles, and publications not available in English were removed, there were 5,105 excluded at title/abstract screen because of irrelevance to the topic (see Figure 1). Strict inclusion/exclusion criteria as outlined above were applied to the full text of 124 articles. Of these, 35 met the full set of criteria and are included in this review.

### Study Methodology

A majority of the articles ( $n = 28$ , 80%) were quantitative studies. Of the quantitative articles, 16 articles (57%) used a cross-sectional design with secondary data analysis to analyze medical records, disability service records, or population-based health surveys (Baloch & Jennings, 2019; Bell et al., 2015; Harrington & Kang, 2008, 2010, 2016; Johansen et al., 2015; Kang & Harrington, 2008; Leigh et al., 2016; Li et al., 2017; Magaña et al., 2016; Nunez-Wallace et al., 2010; Parish et al., 2013; Patel et al., 2016; Sohler et al., 2009; Stancliffe & Lakin, 2006; Woo, 2017). Bershadsky et al. (2014) and Scott and Haverkamp (2014) both analyzed a national survey specific to the I/DD population called the National Core Indicators.

Of those quantitative articles using primary data, 11 articles (39%) collected data from people with I/DD, caregivers/support people, or medical records. Survey data collected from adults with attention deficit hyperactivity disorder (ADHD) examined smoking behaviors (Covey et al., 2010) and ADHD symptoms among college students (D. H. Lee et al., 2008). Survey data were gathered from caregivers and parents/guardians through in-person interviews (Blacher & McIntyre, 2006) and by telephone (Shattuck et al., 2011). Magaña et al. (2002) completed interviews with Puerto Rican adults with I/DD and their mothers and analyzed results quantitatively. Jones et al. (2018) analyzed medical records of pregnant Black women's self-reported behaviors with ADHD. Knoll et al. (2008) evaluated dental X-rays of adults with Down syndrome. C. T. Lee et al. (2015) completed an analysis of the Add Health dataset, which included individuals with ADHD.

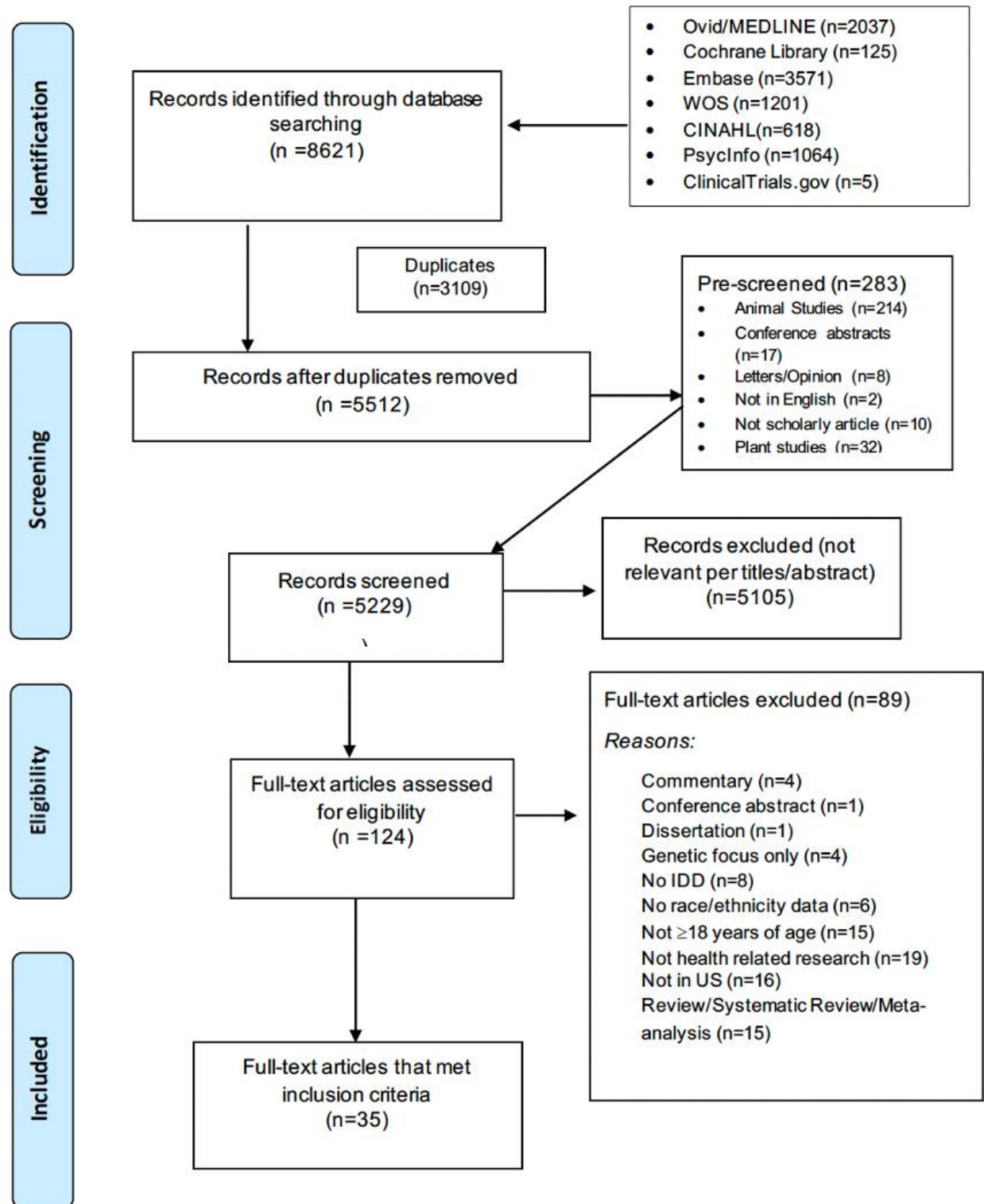
Two quantitative studies analyzed data from observations. Latina mothers of individuals with autism spectrum disorder were asked to collect behavioral information using an evaluation tool, which was analyzed by Magaña and Smith (2013). Horovitz et al. (2013) evaluated adults' behaviors with intellectual disabilities (ID) using an observational tool completed by professionals.

Seven studies (20% of all studies) used qualitative approaches, which included interviews, focus groups, and Photovoice methodology. Bogenschutz (2014) completed interviews with immigrants and refugees with I/DD. Terhune (2005) conducted interviews with Black caregivers of individuals with developmental disabilities. Waite and Tran (2010) completed interviews with ethnically diverse women with ADHD. Baker et al. (2010) completed focus groups with Southeast



Figure 1

Flowchart of the Process of Literature Search and Extraction of Studies Meeting the Inclusion Criteria





Asian caregivers of individuals with developmental disabilities. Jurkowski and Paul-Ward (2007) and Jurkowski et al. (2009) conducted a Photovoice study with Mexican American or Latino adults with I/DD. Lightfoot and Williams (2009) completed focus groups with self-advocates and domestic violence providers in order to identify research strategies for people of color (no definition of race or ethnicity provided by authors), with disabilities who had been victims of violence. Their conclusions suggested approaches on conducting research with people of color who have disabilities, highlighting the importance of including people of color with disabilities throughout all research stages.

### **Geographic Distribution**

Twenty studies (57%) were based in a finite geographic area (one city or one state). Among these, almost half ( $n = 8$ ) were based in California (Baker et al., 2010; Blacher & McIntyre, 2006; Harrington & Kang, 2008, 2010, 2016; Kang & Harrington, 2008; Leigh et al., 2016; Woo, 2017). Four articles evaluated health outcomes specific to one state or city in the Midwest (Bell et al., 2015; Covey et al., 2010; Jurkowski & Paul-Ward, 2007; Jurkowski et al., 2009). Four studies were in states on the east coast (Bogenschutz, 2014; Jones et al., 2018; Knoll et al., 2008; Sohler et al., 2009), and four studies were set in southern states (Horovitz et al., 2013; Nunez-Wallace et al., 2010; Parish et al., 2013; Terhune, 2005). Seven articles (20%) included multiple states or were regional (Li et al., 2017; Magaña et al., 2002; Patel et al., 2016; Scott & Haverkamp, 2014; Stancliffe & Lakin, 2006; Waite & Tran, 2010). Eight articles (23%) had a national focus (Baloch & Jennings, 2019; Bershadsky et al., 2014; Johansen et al., 2015; Lee et al., 2015; Lee et al., 2008; Lightfoot & Williams, 2009; Magana et al., 2016; Shattuck et al., 2011).

### **Data Sources**

We identified the primary source for the research data to clarify if people with I/DD reported directly regarding their health. Twelve of the articles (34%) included data collection directly with individuals with I/DD. Among the quantitative articles that sourced data directly from adults with I/DD ( $n = 7$ ), four articles (Covey et al., 2010; Jones et al., 2018; C. T. Lee et al., 2015; D. H. Lee et al., 2008) had a specific focus on adults with ADHD, with the remaining three including people with I/DD broadly (Bershadsky et al., 2014; Magaña et al., 2002; Scott & Haverkamp, 2014). Adults with I/DD were also directly involved in data collection in qualitative studies ( $n = 5$ ). Four qualitative articles (Bogenschutz, 2014; Jurkowski & Paul-Ward, 2007; Jurkowski et al., 2009; Lightfoot & Williams, 2009) included adults with I/DD, and one article specifically focused on women with ADHD (Waite & Ramsay, 2010). Five articles obtained data directly from caregivers of those with I/DD (Baker et al., 2010; Blacher & McIntyre, 2006; Magaña & Smith, 2013; Shattuck et al., 2011; Terhune, 2005). The remaining 16 articles (46%) completed secondary data analysis of service system data, including health records and social services.

### **Disparities When Comparing Race and/or Ethnicity and Disability Status**

Across a majority ( $n = 29$ , 83%) of the studies, there was some form of disparity reported when comparing people by race or ethnicity to White individuals and/or people with/without

disabilities. Disparities by race and ethnicity were noted in service utilization, access to care, oral health, mental health, social or behavioral outcomes, and culturally responsive approaches to providing care/support. See Table 1 for a summary of study results by outcome of focus.

Three of the articles focused on one race or ethnicity and all three articles were solely focused on individuals who were Black (Bell et al., 2015; Jones et al., 2018; Knoll et al., 2008). Bell et al. found that Black adults diagnosed with I/DD in childhood were more likely to be misdiagnosed in adulthood with psychiatric issues. Jones et al. looked at the relationship between ADHD symptoms, depression, and quality of life among pregnant Black women. Black women with ADHD were more likely to have depression and have a lower quality of life than those adults without ADHD. Knoll et al. looked at the prevalence of periodontitis among Black individuals with Down syndrome and found they had higher rates of gum disease than those without Down syndrome

The remaining articles compared more than one racial or ethnic group. Among these, seven were focused on comparing one group to their White counterparts. Amid the seven comparing one group to their White counterparts, three (Horovitz et al., 2013; Lee et al., 2008; Parish et al., 2013) compared Black individuals to White individuals, three articles (Blacher & McIntyre, 2006; Magaña et al., 2002; Magaña & Smith, 2013) compared Latino individuals to White individuals, and one article (Woo, 2017) compared Asian individuals to White individuals.

The three articles comparing White adults to Black adults varied in what they were comparing, with two articles discussing differences in symptoms and one discussing differences in access to healthcare. Horovitz et al. (2013) found that White adults with I/DD were more likely to have challenging behaviors identified compared to their Black peers with I/DD. In contrast, Black college students were more likely to report ADHD symptoms (inattentive, hyperactive-impulsive) as compared to White students (Lee et al., 2008). When looking at access to care, Parish et al. (2013) identified that White women with I/DD were more likely to receive a mammogram, with rates 3-5 times higher, than Black women with I/DD.

Blacher and McIntyre (2006) found that Latino mothers of adults with I/DD had both higher depressive symptoms and positive feelings about their child compared to White mothers of adults with I/DD. Magaña and Smith (2013) found that Latino individuals with autism spectrum disorder had fewer repetitive behaviors reported by their mothers on the Autism Diagnostic Interview-Revised compared to White individuals and concluded that future research should look at the cultural relevance of these assessment questions. Magaña et al. (2002) found that Puerto Rican adults with I/DD and their families had more unmet service needs as compared to White adults with I/DD. Woo (2017) identified that Asian Americans with I/DD or other mental health conditions were less likely to use mental health services compared to their Non-Hispanic White counterparts.

Twenty articles compared three or more racial or ethnic groups. Bershadsky et al. (2014) used the National Core Indicator data set and initially found differences in getting preventive care by race/ethnicity, with those who were White non-Hispanic having more access to preventive

**Table 1***Summary of Studies (N = 35) Based on Race or Ethnic Analysis Scope and Outcome of Focus*

Author, Year	Race or ethnic analysis scope			Outcome of focus					
	Disparity or difference by race/ethnicity (n = 33)	One race/ethnicity (n = 7)	Two races or ethnic groups (n = 7)	More than two races or ethnic groups (n = 21)	Access to services (n = 16)	Culture (n = 9)	Mental health (n = 6)	Oral health (n = 2)	Social or behavioral (n = 13)
Baker et al., 2010	X	X			X	X			
Baloch & Jennings, 2019	X			X			X		
Bell et al., 2015	X	X					X		
Bershadsky, 2014				X	X				
Blacher et al., 2006	X		X			X	X		
Bogenschutz et al., 2014	X			X	X	X			
Covey et al., 2010	X			X					X
Harrington & Kang, 2008	X			X	X				
Harrington & Kang, 2008	X			X	X				
Harrington & Kang, 2010	X			X	X				
Horovitz et al., 2013	X		X						X
Johansen et al., 2015	X			X					X
Jones et al., 2018	X	X					X		
Jurkowski & Paul-Ward, 2007	X	X			X	X			
Jurkowski et al., 2009	X			X		X	X		X
Kang & Harrington, 2008	X			X	X				

*(table continues)*

Author, Year	Race or ethnic analysis scope				Outcome of focus				
	Disparity or difference by race/ethnicity (n = 33)	One race/ethnicity (n = 7)	Two races or ethnic groups (n = 7)	More than two races or ethnic groups (n = 21)	Access to services (n = 16)	Culture (n = 9)	Mental health (n = 6)	Oral health (n = 2)	Social or behavioral (n = 13)
Knoll et al., 2008	X	X						X	
Lee et al., 2015	X			X					X
Lee et al., 2008	X		X						X
Leigh et al., 2016	X			X	X				
Li, 2017	X			X					X
Lightfoot & Williams, 2008				X		X			X
Magaña et al., 2002	X		X		X				
Magaña & Smith, 2013	X		X			X			X
Magaña et al., 2016	X			X	X				
Nunez-Wallace et al., 2010	X			X	X				
Parish et al., 2013	X		X		X				
Patel et al., 2016	X			X					X
Scott & Havercamp, 2014	X			X	X			X	X
Shattuck et al., 2011	X			X	X				
Sohler et al., 2009	X			X					X
Stancliffe & Lakin, 2006	X			X					X
Terhune, 2005	X	X			X	X			
Waite & Ramsay, 2010	X			X		X			
Woo, 2017	X		X		X		X		

Note. Access to care = Likelihood of care access and service utilization; Culture = Culturally relevant approaches to providing services that impact service use; Mental health = mental health differences; Oral health = oral health outcomes or access; Social or behavioral = Social outcomes like quality of life or behavioral differences related to health outcomes

care services compared to their peers who identified as Black, non-Hispanic, or Hispanic. After controlling for other demographic and personal level variables (diagnoses, mobility, expression, language, living arrangement, and age) the racial/ethnic disparity was no longer statistically significant.

One study pointed to the critical need to develop culturally appropriate education to encourage the use of services among families who are immigrants or refugees (Bogenschutz, 2014). Women from ethnic and minoritized backgrounds, including Black, Hispanic, American Indian, and Asian, with ADHD advocated for more culturally and gender-relevant care (Waite & Ramsay, 2010). When comparing diagnoses of incarcerated populations, Black individuals were more likely to have cognitive disabilities, and White individuals had a higher prevalence of psychosocial disabilities (Baloch & Jennings, 2019). White males with more severe ADHD symptoms were more likely to smoke than males who were non-White (Lee et al., 2015). In evaluating a smoking cessation medication intervention, non-White participants with ADHD had more success with quitting smoking (Covey et al., 2010). Individuals who were Black, Hispanic, or Asian with ADHD had lower rates of use of ADHD medication, which may be because of a lack of a usual source of care (Johansen et al., 2015). Individuals with ADHD from minoritized racial or ethnic groups were less likely to start or maintain the use of medications (Li et al., 2017). Adults who were Black with I/DD were less likely to adhere to diabetes medication compared to White adults with I/DD (Patel et al., 2016).

Five studies involving secondary analyses of disability service system data from California examined differences among racial/ethnic groups. Overall, racial/ethnic minoritized individuals with I/DD received fewer services than White individuals with I/DD (Harrington & Kang, 2008, 2010; Kang & Harrington, 2008). In a follow-up study by Harrington and Kang (2010), they found that people with I/DD with racially or ethnically minoritized identities were more likely to receive personal care services than White individuals, although they were more likely to be approved for less total hours of personal care service compared to their White counterparts (Harrington & Kang, 2010). An analysis of disability service system data also identified that White individuals with autism spectrum disorder received more services than those from racial or ethnic minoritized groups (Leigh et al., 2016).

Studies of secondary health data reveal disparities or differences between people when analysis was completed comparing people by race or ethnicity. In evaluating health data from 25 states, adults with I/DD who also identified as being a member of a minoritized racial/ethnic group were less likely to have visited a dentist or general practitioner or receive a flu shot (Scott & Haverkamp, 2014). In contrast, Black women with I/DD were more likely to receive a mammogram than other racial/ethnic groups, and Hispanic people with I/DD were less likely to participate in cancer screenings than White individuals with I/DD (Scott & Haverkamp, 2014).

In other research, White adults with I/DD had higher quality of life evaluation scores (health, making choices, seeing friends, happiness, safety) than Blacks with I/DD (Stancliffe & Lakin, 2006). An analysis of post-high school outcomes among individuals with autism spectrum disorder found that Black young adults with autism spectrum disorder were less likely to get

speech therapy, case management, mental health services, and medical evaluations compared to their White peers (Shattuck et al., 2011). Finally, when a conservator was in place to make medical decisions for adults with profound I/DD, the race/ethnicity of the individual with I/DD was not related to consent for treatment. Still, Black conservators were less likely to approve treatment than White conservators (Nunez-Wallace et al., 2010). Black and Hispanic adults with I/DD were more likely to be overweight or obese compared to White adults with I/DD (Magaña et al., 2016; Sohler et al., 2009).

### **Understanding the Different Experiences with Disability**

Four studies aimed to understand the different experiences of racial-ethnic minoritized people with I/DD and their supporters. Terhune (2005) listened to the perspectives of low-income Black caregivers of adults with I/DD regarding service use. In Terhune's study, Black caregivers who identified with secular worldviews were more likely to use formal disability services compared to caregivers with a spiritual worldview. Those who identified as having spiritual worldviews were more likely to report using informal support. Terhune also identified the need to reframe disability services outside of the medical model.

Baker et al. (2010) conducted a qualitative community-based participatory research project that addressed the understanding of developmental disability and disability service systems among Hmong-Mien families. They found that Hmong-Mien caregivers and providers for individuals with I/DD lacked trust in disability service systems. Jurkowski and Paul-Ward (2007) found that being a Mexican American with I/DD born in the U.S. meant that those individuals were more likely to obtain health services as compared to Mexican-born Mexican Americans with I/DD. Latino individuals with I/DD wanted health services to be more holistic and inclusive of mental health and social life (Jurkowski et al., 2009).

### **Discussion**

Researchers in the disability research and advocacy world have called for an intersectional approach to understanding the experience of disability (Banks, 2018; Warner & Brown, 2011). This scoping review presented research in which most findings are not framed considering intersectionality, but rather primarily describing differences in health experiences and outcomes among people with I/DD who identify as living with a racial or ethnic minoritized status. Many studies reported health differences or disparities between minoritized individuals with I/DD and those who identify as White and/or people with and without disabilities. While knowledge of disparities is important, this knowledge does not consider the entirety of individuals' experiences. Therefore, recognition for how the intersection between disability and race/ethnicity often results in marginalization, especially for people of color is needed (Annamma et al., 2013). Future research should focus on the intersection between racial/ethnic minoritized individuals who have a disability and how these social constructs create unique health experiences among racial and ethnic minoritized individuals with I/DD. As an initial step, research should use an intersectionality approach to describe the experiences of minoritized populations

with disabilities related to structural and societal barriers (Frederick & Shifrer, 2019; Hankivsky, 2012).

Additionally, our findings highlight the importance of early access to health care to prevent comorbid conditions and premature death. Adults with I/DD also have higher rates of comorbid conditions that could have been prevented or ameliorated if there had been access to care (Cooper et al, 2025; Haverkamp et al., 2004; Lauer & McCallion, 2015; Reichard et al., 2011). Many individuals with I/DD who have racially and ethnically minoritized identities do not have a regular care provider, which can impact adherence to health care, such as taking prescribed medication (Johansen et al., 2015).

This scoping review also highlights the missed opportunities for collecting self-reported data from people with I/DD. Qualitative research methods play an important role in incorporating individuals' voices from underrepresented populations such as individuals with I/DD. These methods may enhance a lack of data from smaller populations such as American Indian/Alaska Natives, which are frequently unable to be identified from large data sets because of incomplete data. Incomplete data may result from the U.S. federal government's inattention to supporting data sovereignty among tribes, which could generate more complete data sets (Carroll et al., 2020).

Research calls have been made to increase participation from individuals with I/DD as research partners and/or as participants (Beail & Williams, 2014; Caldwell, 2014). As such, community-based approaches are recommended when engaging with community members to conduct research. Community-based and participatory methodologies can fill a significant gap in creating culturally responsive research to inform healthcare and health promotion practices (Wallerstein et al., 2019). Community-based approaches have provided insight into the lives of individuals with I/DD, using methods such as Photovoice (Williamson et al., 2020). In this study, individuals used photography to share their stories about an issue, thus maximizing the strengths of nonuniversity-based co-researchers with I/DD. Although significant time is needed for this approach, including educating Institutional Review Boards about research with people who have I/DD as engaged research participants and partners, the inclusion of community voices is necessary. The authors recognize the opportunities for building innovative knowledge about, with, and for people with I/DD when researchers are open to novel methodologies.

## Conclusions

This scoping review highlights existing research focused on racially/ethnically minoritized adults with I/DD. While there is a body of literature dedicated to understanding health and inequity experienced by racially/ethnically minoritized adults with I/DD, this literature is by no means robust. Most of the research highlights health disparities or health differences between racially/ethnically minoritized adults with I/DD and adults who were White with I/DD. The results of this scoping review indicate that researchers should be intentional about the inclusion of racial/ethnic minoritized groups with I/DD and consider using novel methodologies that enhance historically marginalized voices as both research partners and research participants.



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