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

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Keywords: intellectual disability, developmental disabilities, race, ethnicity, health disparities
Abstract

Among U.S. adults with disabilities, the prevalence of disability varies by race and ethnicity, with White adults reporting less disability than historically marginalized racial/ethnic groups. Living with intersectional identities, having a disability, and being a member of a racial or ethnic minority group creates marginalization that may contribute to health disparities. Previous research indicates there is limited intersectional disability research conducted in the U.S., as the prevailing approach focuses on disability broadly. Even less is understood about adults with intellectual and developmental disabilities (IDD) living with intersectional identities. The purpose of this scoping literature review is to describe health research regarding adult racial/ethnic minoritized individuals with IDD in the U.S. Nine databases were used for the search. Search terms included those related to racial/ethnic status, IDD diagnosis, and health. The review resulted in 35 articles meeting the inclusion criteria. Thirty-three of the 35 articles identified disparities experienced by adults with IDD from racial/ethnic minoritized groups. Results highlight the lack of research focused on racially/ethnically minoritized adults with IDD. The results of this scoping review indicate that researchers must be intentional about the inclusion of racial/ethnic minoritized groups with IDD and include novel methodologies that enhance historically marginalized voices. Researchers should incorporate existing data to highlight service gaps that influence poor health outcomes among minoritized individuals with IDD. Research highlighting service gaps may provide critical information for practitioners working to address health needs for special populations with IDD.

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

In this scoping review, we aim to describe the recent health research areas among adult (ages 18 and up) racial/ethnic minorities with intellectual and developmental disabilities (IDD) in the United States. We specifically focus on health research with adults with IDD because adulthood among people with IDD is an area in need of attention. Much research on IDD focuses on youth, perhaps due to a robust field of special education programming and research, leaving the health needs, assets, and concerns of adults with IDD unrecognized. After age 22 in the United States, when adults with IDD "age out" of special education, some have noted that young adults fall off "the disability cliff," into "an underfunded and uncoordinated system," which includes the health care system (Bagenstos, 2015).

In this review, we also consider the intersection between racial/ethnic minoritized status and disability status and how these social constructs create different health experiences among racial and ethnic minorities with disabilities. Through this lens of intersectionality (Frederick & Shifrer, 2018; Hankivsky, 2012), we sought out to assess research that provides insight into the variety of experiences of minoritized populations with disabilities. Additionally, this work is informed by the social model of disability that reframes disability as resulting from environmental or attitudinal barriers (e.g., lack of American Sign Language interpreters or accessible buildings, stigma, bias), which influence the health outcomes of individuals with disabilities (Goering, 2015).

State of Disability in the U.S.

Approximately 60 million (one in four) adults in the U.S. report living with a disability (CDC, 2020 including impairments with vision, hearing, mobility, and cognition (CDC, 2020).
Among U.S. adults living with disabilities, prevalence varies by race and ethnicity, with 10% of Asian-American adults reporting a disability compared to 20% American Indian/Alaska Native adults (CDC, 2020 & Courtney-Long et al., 2017). White, Asian American and Pacific Islander adults report less disability (24.4%, 16.4%, and 25.4% respectively) than Black/African American (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 minority groups in the U.S., as the prevailing approach is to focus on disability first and racial identity second (Frederick and Shifrer, 2018).

Intellectual and developmental disabilities (IDD) are diagnosed before the age of 18. Intellectual disability (I.D.) is characterized by significant limitations in intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical adaptive skills (American Association of Intellectual and Developmental Disabilities, 2008; Krahn & Fox, 2014). The population of individuals with IDD makes up a small number of individuals in the U.S. and has experienced a long history of institutionalization and medical mistreatment (Rembis, Kudlick, Neilsen & Rembis 2018; Krahn, Walker & Correa-De-Araujo, 2015). Data from the 2015-2016 National Health Interview Survey (NHIS) indicate that 17.8% of children have developmental disabilities and 1.2% have experience I.D. (Zablotsky et al., 2019). Health surveillance among individuals with IDD in the U.S. is often limited to people who are connected to the service system (Havercamp & Scott, 2019); however, it is estimated that nearly 70% of people with IDD are not connected to this system (Bonardi, Krahn & Morris, 2019; Braddock, Hemp, Rizzolo, Haffer, Tanis & Wu, 2015). More recent research acknowledges the limits of existing surveillance efforts and uses administrative claims data to assess health outcomes for people with
Health Research with Racially/Ethnically Adults with IDD (Havercamp & Scott, 2019). Further researchers call for more inclusive disability data collection practices (Mitra, 2013). For example, in national surveys such as the National Core Indicators Consumer Survey, there are screener questions, where in many cases, adults with IDD are not reached because they are unlikely to respond to telephone surveys (Havercamp & Scott 2019). Similarly, the National Health Interview Survey (NHIS) does not sample in some locations where adults with IDD 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, Walker & Correa-De-Araujo, 2015). Health disparities are defined as differences in health outcomes and their determinants between segments of the population are defined by social, demographic, environmental, and geographical attributes (Krahn, Walker & Correa-De-Araujo, 2015). These determinants include race and ethnicity, age, language, sex or gender, socioeconomic status, access to healthcare, and a lack of education, all of which can influence the health status of those with disabilities (Krahn, Walker & Correa-De-Araujo, 2015). As a group, people with disabilities fare worse than their nondisabled counterparts across a broad range of health indicators (Krahn, Walker & Correa-De-Araujo, 2015). For example, adults living with disabilities are more likely to be obese (38.2 compared to 26.2% of adults without disability), smoke (28.2% compared to 13.4% of adults without disability), have heart disease (11.5% compared to 3.8% of adults without disability) and have diabetes (16.3% compared to 7.2% of adults without disability) (CDC, 2018).

Intersectionality (IDD and Race/Ethnicity)

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
The intersection of disability and race/ethnicity refers to the intersectionality framework, which examines how dynamics of inequality are mutually constituted (Fredrick & Shifrer, 2018) and considers interactions between different aspects of social identity (Hankivsky, 2012). The intersection between disability and race/ethnicity often results in marginalization, especially for people of color (Annamma, Connor & Ferri, 2012).

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 IDD and identify gaps in the literature to set a research agenda moving forward.

**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). Although there are clinical trials and other types of health-related research that inform our understanding and care of persons with IDD and diverse racial/ethnic populations, there is a dearth of information regarding how these two social constructs (IDD, race/ethnicity) impact each other. Because this intersection includes unchartered territory, we felt that a scoping review methodology would best address our broad questions. 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. (2018), 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.

We thus planned and performed a scoping review, using the "PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation" (Tricco et al., 2018) as our reporting guide.

**Eligibility Criteria**

Studies were included if they focused on adults with IDD and had demographic information about race and/or ethnicity. Only studies in English conducted in the United States 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 IDD; 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 non-scholarly publications were also excluded.

**Search Strategy**

A medical librarian (CLH) searched the following databases for publications addressing IDD 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. Publications were limited to those published between January 1, 2000 to March 26, 2019 (the date the searches were completed). An English language filter was applied to all the searches. The search strategy
used in Ovid/MEDLINE, which was adapted for use in the other databases, is available in Appendix A.

**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 pre-screened and excluded animal/plant studies, conference abstracts, letters and opinion pieces, articles not available in English, and non-scholarly articles such as newspaper reports.

Two teams of screeners (TC-J; JE/SS/LKL) independently screened all titles and abstracts of retrieved references for relevance to our questions. Disagreements were resolved by consultation with one of three third reviewers (MSL, JSA, or HJW). 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 (TC-J; SS/LKL). Disagreements were resolved by consultation with one of the three third reviewers (MSL, JSA, or HJW).

**Data Extraction**

After screening, two of the reviewers (S.S. and LKL) 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, IDD diagnosis); intervention (description and setting); data measurement tool; study length; study location; and results.
Results

We found 8621 records through database searches (Ovid/MEDLINE 2037; Cochrane Library 125; Embase 3571; WOS 1201; CINAHL 618; PsycInfo 1064; ClinicalTrials.gov 5). Of the 5229 publications that remained after duplicates, animal/plant studies, conference abstracts, letters, non-scholarly articles, and publications not available in English were removed, 5105 were excluded at title/abstract screen because of irrelevance to the topic (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.

Insert figure 1 here.

Study Methodology & Geographic Distribution

Many of the articles (n=28) were quantitative studies. Among the quantitative articles, sixteen articles 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, Jackson & Bell, 2015; Harrington & Kang, 2008; Harrington & Kang, 2010; Harrington & Kang, 2016; Johansen, Matic & McAlearney, 2015; Kang & Harrington, 2008; Leigh, Grosse, Cassady, Melnikow & Hertz-Picciotto, 2016; Li, Liu, Zhu, Liu & Winterstein, 2017; Magana, Parish, Morales, Li & Fujiura, 2016; Nunez-Wallace, Gill, Harrison, Taylor & Charles, 2010; Parish, Swaine, Son & Luken, 2013; Patel et al., 2016; Sohler, Lubetkin, Levy, Soghomonian & Rimmerman, 2009; Stancliffe & Lakin, 2006; Woo, 2017). Bershadsky, Hiersteiner, Fay & Bradley (2014) and Scott & Havercamp (2014) both analyzed a national survey specific to the IDD population called the National Core Indicators.

Of those articles using primary data, eleven articles collected data from people with IDD, 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 (Lee, Oakland, Jackson & Glutting, 2008). Survey data were gathered from caregivers and parents/guardians through in-person interviews (Blacher & McIntyre, 2006) and by telephone (Shattuck, Wagner, Narendorf, Sterzing & Hensley, 2011). Magana, Seltzer & Krauss (2002) completed interviews with Puerto Rican adults with I.D. and their mothers and analyzed results quantitatively. Jones et al. (2018) analyzed medical records of pregnant African American women's self-reported behaviors with ADHD. Knoll, Janal, & Khocht (2009) evaluated dental x-rays of adults with Down Syndrome. Lee, Clark, Kollins, McClemon & Fuemmeler (2015) completed an analysis of the Add Health dataset, which included individuals with ADHD.

Two studies analyzed data from observations. Latina mothers of individuals with Autism Spectrum Disorder (ASD) were asked to collect behavioral information using an evaluation tool, which was analyzed by Magana & Smith (2013). Horovitz, Matson, Hattier, Tureck & Bamburg (2013) evaluated adults' behaviors with I.D. using an observational tool completed by professionals.

Paul-Ward (2007) and Jurkowski, Rivera & Hammel (2009) conducted a Photovoice study with Mexican American or Latino adults with IDD.

Twenty studies were based in a finite geographic area (one city or one state). Among these, eight were based in California (Baker et al., 2010; Blacher & McIntyre, 2006; Harrington & Kang, 2008; Harrington & Kang, 2010; Harrington & Kang, 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, Jackson & Bell, 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, Janal & Khocht, 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, et al, 2005). Seven articles included multiple states or were regional (Li et al., 2017; Magana et al., 2002; Magana & Smith, 2013; Patel et al., 2016; Scott & Havercamp, 2014; Stancliffe & Lakin, 2006; Waite & Ramsay, 2010). Eight articles had a national focus (Baloch & Jennings, 2019; Bershadsky et al., 2014; Johansen et al., 2015; Lee et al., 2008; Lee et al., 2015; Lightfoot & Williams, 2008; Magana et al., 2016; Shattuck et al., 2011).

**Data Sources**

Considering the disability rights movement and the "nothing about us without us" principle in disability activism, we identified the primary source for the research data to clarify if people with IDD reported directly regarding their health. Twelve of the articles included data collection directly with individuals with IDD. Among the quantitative articles that sourced data directly from adults with IDD (N=7), four articles (Covey et al., 2010; Jones et al., 2018; Lee et al., 2008; Lee et al., 2015) had a specific focus on adults with ADHD, with the remaining three including people with IDD broadly (Bershadsky et al., 2014; Magana et al., 2002; Scott &
Havercamp, 2014). Adults with IDD 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, 2008) included adults with IDD, and one article
specifically focused on women with ADHD (Waite & Ramsay, 2010). Five articles obtained data
directly from caregivers of those with IDD (Baker et al., 2010; Blacher & McIntyre, 2006;
Magana & Smith, 2013; Shattuck et al., 2011; Terhune, 2005). The remaining sixteen articles
completed secondary data analysis of service system data, including health records and social
services.

Disparities Related to Race or Ethnicity

Across a majority (n=33) of the studies, there was some form of disparity reported related
to race or ethnicity. 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. Two articles were found not to have a disparity-specific outcome related to race or
ethnicity. Bershadsky et al. (2014) used the national NCI data set and initially found differences
in getting preventive care by race/ethnicity, with non-Hispanic Whites accessing more preventive
care services. After controlling for other demographic variables, the racial/ethnic disparity was
no longer statistically significant. Lightfoot & Williams (2008) focused on identifying research
strategies for people of color with disabilities who have been victims of violence. Their
conclusions suggested approaches on conducting research with this population, highlighting the
importance of including people of color with disabilities throughout all research stages.

Seven of the articles focused on one race or ethnicity. Among these, four articles were
solely focused on individuals who were African American (Bell et al., 2015; Jones et al., 2018;
Knoll et al., 2008; Terhune, 2005), one focused on families who spoke Hmong-Mien (Baker et al., 2010), one focused on Mexican Americans (Jurkowski & Paul-Ward, 2007) with I.D., and one focused on Latinos with I.D. (Jurkowski et al., 2009). Bell et al. (2015) found that African American adults diagnosed with IDD in childhood were more likely to be misdiagnosed in adulthood with psychiatric issues. Jones et al. (2018) looked at the relationship between ADHD symptoms, depression, and quality of life among pregnant African American women. African American women with ADHD were more likely to have depression and have a lower quality of life than those adults without ADHD. Knoll et al. (2008) looked at the prevalence of periodontitis among African American individuals with Down Syndrome and found they had higher rates of gum disease than those without Down Syndrome. Terhune (2005) listened to the perspectives of low-income African American caregivers of adults with IDD regarding service use. In Terhune's study, African American 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 (D.D.) and disability service systems among Hmong-Mien families. Baker et al. (2010) found that Hmong-Mien caregivers and providers for individuals with D.D. noted a lack of trust in disability service systems. Jurkowski & Paul-Ward (2007) found that being a Mexican American with an I.D. born in the U.S. meant that those individuals were more likely to get health services as compared to
Mexican-born Mexican Americans with I.D. Latinos with I.D. wanted health services to be more holistic and inclusive of mental health and social life (Jurkowski et al., 2009).

The remaining twenty-eight 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., 2012; Lee et al., 2008; Parish et al., 2013) compared African Americans to Whites, three articles (Blacher et al., 2006; Magana et al., 2002; Magana & Smith, 2013) compared Latinos to Whites, and one article (Woo, 2017) compared Asians to Whites. White adults with I.D. were more likely to have challenging behaviors compared to African American individuals with I.D. (Horovitz et al., 2012). African American college students were more likely to report ADHD symptoms as compared to White students (Lee et al., 2008). Parish and colleagues (2013) identified that White women with I.D. were more likely to receive a mammogram, with rates 3-5 times higher, than African American women with I.D. Blacher et al. (2006) found that Latino mothers of adults with I.D. had both higher depressive symptoms and positive feelings about their child compared to White mothers of adults with I.D. Magana & Smith (2013) found that Latino individuals with ASD had fewer repetitive behaviors reported by their mothers on the Autism Diagnostic Interview-Revised compared to Whites and concluded that future research should look at the cultural relevance of these assessment questions. Magana et al. (2002) found that Puerto Rican adults with I.D. and their families had more unmet service needs as compared to White adults with I.D. Woo (2017) identified that Asian Americans with I.D. or other mental health conditions were less likely to use mental health services compared to their Non-Hispanic White counterparts.
Twenty-one articles compared three or more racial or ethnic groups. Two studies pointed to the critical need to develop culturally appropriate education to encourage the use of services among families who are immigrants or refugees (Baker et al., 2010; Bogenschutz et al., 2014). Women from ethnic and minority backgrounds, including African American, Hispanic, American Indian, and Asian, and with ADHD advocated for more culturally and gender-relevant care (Waite & Ramsay, 2010). When comparing diagnoses of incarcerated populations, African Americans were more likely to have cognitive disabilities, and Whites had a higher prevalence of psychosocial disabilities (Baloch & Jennings, 2019). White males with more severe ADHD symptoms were more likely to smoke than non-White males (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). African American, Hispanic, and Asian individuals with ADHD had lower rates of use of ADHD medication, which may be due to 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). African American adults with D.D. were less likely to adhere to diabetes medication compared to White adults with D.D. (Patel et al., 2016).

Five studies involved a secondary analysis of disability service system data from California examining differences among racial/ethnic groups. In California, racial/ethnic minoritized individuals with IDD received fewer services than Whites with IDD (Harrington & Kang, 2008; Harrington & Kang, 2010, Kang & Harrington, 2008). Also, in California, racial/ethnic minority groups were more likely to receive personal care services than Whites but received fewer personal care service hours approved than Whites (Harrington & Kang, 2010).
An analysis of disability service system data also identified that Whites with an ASD received more services than those from racial or ethnic minority groups (Leigh et al., 2016).

Studies of secondary health data reveal suboptimal health outcomes for people of color with disabilities. In evaluating health data from twenty-five states, adults with IDD 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 to receive a flu shot (Scott & Havercamp, 2014). African American women with IDD were more likely to receive a mammogram than other racial/ethnic groups, and Hispanic people with IDD were less likely to participate in cancer screenings than Whites (Scott & Havercamp, 2014). An analysis of post-high school outcomes among individuals with ASD found that African American young adults with ASD 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.D., the race/ethnicity of the individual with I.D. was not related to consent for treatment. Still, African American conservators were less likely to approve treatment than White conservators (Nunez-Wallace et al., 2010). Latino and Black adults with IDD had poorer health outcomes compared to White individuals with IDD (Magana et al., 2016). Black and Hispanic adults with IDD were more likely to be overweight or obese compared to White adults with IDD (Magana et al., 2016; Sohler et al., 2009). In other research, Whites with IDD had a higher quality of life evaluation scores than African Americans with IDD (Stancliffe & Lakin, 2006).

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). Our findings point to the importance of concentrated funding supporting equity-focused research identifying health promotion gaps for minoritized racial/ethnic groups with IDD. A significant number of diverse policies and funding for IDD services exist state-by-state; state-focused research can highlight areas for improving equity, particularly in service utilization, which can help address the social determinants of health and facilitate access to health-promoting activities (e.g., community inclusion). For example, Harrington and colleagues (2008) found that racial/ethnic minoritized people with IDD were less likely to receive services, and services were funded at lower rates than White people with IDD in California. Half of the articles that focused exclusively on California were from Harrington's research team, which had received a grant from the National Institute for Disability and Rehabilitation Research (currently National Institute on Disability, Independent Living, and Rehabilitation Research) to explore service utilization and expenditures in California, with the explicit goal of examining "the number and types of individuals with IDD living at home or in the community in California in terms of their predisposing socio-demographic characteristics (e.g., age, gender, race/ethnicity, language)" (National Rehabilitation and Information Center, 2005). Their research program follows the National Center on Cultural Competence's articulation of disparities in service and supports as disparities in availability, accessibility, acceptability, quality, and utilization (National Center for Cultural Competence, 2020). Intentional research by race/ethnicity serves to examine the distribution of disability resources in California, which is known to be one of the lowest in terms of expenditures for these resources (Tanis et al., 2020).
Additionally, our findings highlight the importance of early access to health care as a means to prevent comorbid conditions and premature death. Adults with IDD experience more comorbidities and shorter lifespans as compared to the general population (Cooper et al. 2015), yet access to health care among adults with IDD remains low. Many racial/ethnic minority groups with IDD do not have a regular care provider, which can impact adherence to health care, such as taking prescribed medication (Johansen et al., 2015). Adults with IDD also have higher rates of comorbid conditions that could have been prevented or ameliorated if there had been access to care (Reichard, Stolzle & Fox, 2011; Lauer & McCallion, 2015; Havercamp, Scandlin & Roth, 2004).

This scoping review highlights the missed opportunities for collecting self-reported data from people with IDD. Qualitative research methods play an important role in incorporating individuals' voices from underrepresented populations such as individuals with IDD. These methods may enhance a lack of data from smaller populations such as American Indian/Alaska Natives, which are frequently omitted from large data sets due to 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, Rodriquez-Lonebear & Martinez, 2019). Qualitative and community-based approaches have provided insight into the lives of individuals with IDD, using methods such as Photovoice (Williamson, van Heuman & Schwartz, 2019). Research has yet to increase participation from individuals with IDD as research participants (Caldwell, 2013; Beail & Williams, 2014). Innovative approaches that are inclusive of individuals with IDD must be considered. Williamson, van Heumen & Schwartz (2020) utilized Photovoice, a method in which individuals use photography to share their stories about an issue, thus maximizing the strengths of non-university-based co-researchers with IDD.
The authors acknowledge the significant amounts of time required for this approach, including educating Institutional Review Boards about research with people with IDD as engaged research participants. The authors recognize the opportunities for building innovative knowledge about, with, and for people with IDD when researchers are open to novel methodologies. Qualitative and participatory methodologies can also fill a significant gap in culturally responsive research and services.

**Conclusions**

This scoping review highlights the lack of existing research focused on racially/ethnically minoritized adults with IDD. A majority of the IDD research focuses on children with IDD, the impacts of parenting a child with IDD and exploring the genetic conditions that cause IDD. While there is a growing body of literature dedicated to understanding health, inequity experienced by racially/ethnically minoritized adults with IDD, this literature is by no means robust. Future attention should also focus on the social determinants of health in disability research. The results of this scoping review indicate that researchers should be intentional about the inclusion of racial/ethnic minoritized groups with IDD and include novel methodologies that enhance historically marginalized voices. Moreover, researchers must use existing data to highlight service gaps that influence poor health outcomes among people with disabilities. Research highlighting service gaps may provide critical information for practitioners to address health needs for special populations with IDD.
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HEALTH RESEARCH WITH RACIALLY/ETHNICALLY ADULTS WITH IDD


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Figure 1: Flowchart of the process of literature search and extraction of studies meeting the inclusion criteria

Records identified through database searching (n = 8621)

Records after duplicates removed (n = 5512)

Records screened (n = 5229)

Full-text articles assessed for eligibility (n = 124)

Full-text articles that met inclusion criteria (n = 35)

Pre-screened (n = 283)
- Animal Studies (n = 214)
- Conference abstracts (n = 17)
- Letters/Opinion (n = 8)
- Not in English (n = 2)
- Not scholarly article (n = 10)
- Plant studies (n = 32)

Records excluded (not relevant per titles/abstract) (n = 5105)

Full-text articles excluded (n = 89)

Reasons:
- Commentary (n = 4)
- Conference abstract (n = 1)
- Dissertation (n = 1)
- Genetic focus only (n = 4)
- No IDD (n = 8)
- No race/ethnicity data (n = 6)
- Not ≥18 years of age (n = 15)
- Not health related research (n = 19)
- Not in US (n = 16)
- Review/Systematic Review/Meta-analysis (n = 15)

• Ovid/MEDLINE (n = 2037)
• Cochrane Library (n = 125)
• Embase (n = 3571)
• WOS (n = 1201)
• CINAHL (n = 618)
• PsycInfo (n = 1064)
• ClinicalTrials.gov (n = 5)
Table 1

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

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Race or Ethnic Analysis Scope</th>
<th>Outcome of Focus*</th>
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<tr>
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<td>Disparity by Race or Ethnicity (n=33)</td>
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<td>Li, 2017</td>
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*Access to care=Likelihood of care access and service utilization; Culture=Culturally relevant approaches to providing services which 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*