

A Scoping Review of Health Research with Racially/Ethnically Minoritized Adults with Intellectual and Developmental Disabilities (IDD)
Tara M. Chico-Jarillo¹, Samantha Sasse², Leticia Lelli², Jennifer R. Etcitty³, Carol L. Howe⁴,
Michele S. Lee⁵, Heather J. Williamson^{2,3,5}, Julie S. Armin⁴

¹College of Public Health, University of Arizona

²Department of Occupational Therapy, Northern Arizona University

³Center for Health Equity Research, Northern Arizona University

⁴Family & Community Medicine, College of Medicine, University of Arizona

⁵Institute for Human Development, Northern Arizona University

- 1) Tara M. Chico-Jarillo, MPH, is a Doctoral of Public Health Candidate at the University of Arizona in Tucson, Arizona, United States.
- 2) Samantha Sasse, BS, is an Occupational Therapy Doctoral Student at Northern Arizona University in Phoenix, Arizona, United States.
- 3) Leticia Lelli, BS, is an Occupational Therapy Doctoral Student at Northern Arizona University in Phoenix, Arizona, United States.
- 4) Carol L. Howe, MD, MLS, is a medical librarian at the University of Arizona Health Sciences Library, Tucson, Arizona, United States.
- 5) Jennifer R. Etcitty, BS, is a Master of Public Health student at Northern Arizona University in Flagstaff, Arizona, United States.
- 6) Michele S. Lee, MA, is a PhD student in Interdisciplinary Health at Northern Arizona University in Flagstaff, Arizona, United States.
- 7) Heather J. Williamson, DrPH, FAAIDD, is an Assistant Professor at Northern Arizona University in Flagstaff, Arizona, United States.
- 8) Julie S. Armin, PhD, is an Assistant Professor at the University of Arizona in Tucson, Arizona, United States.

Funding Information: Research reported in this publication was supported by the National Cancer Institute of the National Institutes of Health under the awards for the Partnership of Native American Cancer Prevention U54CA143924 (UACC) and U54CA143925 (NAU).

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

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26

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.

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

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

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

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

47 **State of Disability in the U.S.**

48 Approximately 60 million (one in four) adults in the U.S. report living with a disability
49 (CDC, 2020 including impairments with vision, hearing, mobility, and cognition (CDC, 2020).

50 Among U.S. adults living with disabilities, prevalence varies by race and ethnicity, with 10% of
51 Asian-American adults reporting a disability compared to 20% American Indian/Alaska Native
52 adults (CDC, 2020 & Courtney-Long et al., 2017). White, Asian American and Pacific Islander
53 adults report less disability (24.4%, 16.4%, and 25.4% respectively) than Black/African
54 American (30.2%), Hispanic/Latinx (31.3%), American Indian/Alaska Native (39.9%), and
55 multiracial (35.8%) adults (CDC, 2020). Previous research indicates a general lack of disability
56 research conducted with a focus on racial and ethnic minority groups in the U.S., as the
57 prevailing approach is to focus on disability first and racial identity second (Frederick and
58 Shifrer, 2018).

59 Intellectual and developmental disabilities (IDD) are diagnosed before the age of 18.
60 Intellectual disability (I.D.) is characterized by significant limitations in intellectual functioning
61 and adaptive behavior as expressed in conceptual, social, and practical adaptive skills (American
62 Association of Intellectual and Developmental Disabilities, 2008; Krahn & Fox, 2014). The
63 population of individuals with IDD makes up a small number of individuals in the U.S. and has
64 experienced a long history of institutionalization and medical mistreatment (Rembis, Kudlick,
65 Neilsen & Rembis 2018; Krahn, Walker & Correa-De-Araujo, 2015). Data from the 2015-2016
66 National Health Interview Survey (NHIS) indicate that 17.8% of children have developmental
67 disabilities and 1.2% have experience I.D. (Zablotsky et al., 2019). Health surveillance among
68 individuals with IDD in the U.S. is often limited to people who are connected to the service
69 system (Havercamp & Scott, 2019); however, it is estimated that nearly 70% of people with IDD
70 are not connected to this system (Bonardi, Krahn & Morris, 2019; Braddock, Hemp, Rizzolo,
71 Haffer, Tanis & Wu, 2015). More recent research acknowledges the limits of existing
72 surveillance efforts and uses administrative claims data to assess health outcomes for people with

73 IDD (Havercamp & Scott, 2019). Further researchers call for more inclusive disability data
74 collection practices (Mitra, 2013). For example, in national surveys such as the National Core
75 Indicators Consumer Survey, there are screener questions, where in many cases, adults with IDD
76 are not reached because they are unlikely to respond to telephone surveys (Havercamp & Scott
77 2019). Similarly, the National Health Interview Survey (NHIS) does not sample in some
78 locations where adults with IDD may live (e.g., nursing homes, group homes) (CDC, 2020).

79 **Health Disparities among People with Disabilities**

80 There is a growing body of evidence documenting health disparities by disability status
81 (Krahn, Walker & Correa-De-Araujo, 2015). Health disparities are defined as differences in
82 health outcomes and their determinants between segments of the population are defined by
83 social, demographic, environmental, and geographical attributes (Krahn, Walker & Correa-De-
84 Araujo, 2015). These determinants include race and ethnicity, age, language, sex or gender,
85 socioeconomic status, access to healthcare, and a lack of education, all of which can influence
86 the health status of those with disabilities (Krahn, Walker & Correa-De-Araujo, 2015). As a
87 group, people with disabilities fare worse than their nondisabled counterparts across a broad
88 range of health indicators (Krahn, Walker & Correa-De-Araujo, 2015). For example, adults
89 living with disabilities are more likely to be obese (38.2 compared to 26.2% of adults without
90 disability), smoke (28.2% compared to 13.4% of adults without disability), have heart disease
91 (11.5% compared to 3.8% of adults without disability) and have diabetes (16.3% compared to
92 7.2% of adults without disability) (CDC, 2018).

93 **Intersectionality (IDD and Race/Ethnicity)**

94 Similar to health disparities among people with disabilities, there is a growing body of
95 evidence that suggests the social construction of disability is influenced by one's racial/ethnic

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

101 The objective of this scoping review is to provide a summary of the existing literature in
102 the area of health research with racially/ethnically minoritized adults with IDD and identify gaps
103 in the literature to set a research agenda moving forward.

104 **Methods**

105 A scoping review was completed instead of a systematic review, as the study team
106 wanted to characterize the scope of the research literature rather than evaluating the quality of
107 the research literature (Munn et al., 2018). Although there are clinical trials and other types of
108 health-related research that inform our understanding and care of persons with IDD and diverse
109 racial/ethnic populations, there is a dearth of information regarding how these two social
110 constructs (IDD, race/ethnicity) impact each other. Because this intersection includes
111 uncharted territory, we felt that a scoping review methodology would best address our broad
112 questions. Specifically, we considered that our topic met at least five of the six indications for
113 conducting a scoping review rather than a systematic review as outlined by Munn et al. (2018),
114 namely: 1) to identify as much related literature as possible; 2) to clarify concepts and
115 definitions; 3) to see how previous research has been conducted; 4) to uncover related
116 characteristics/factors, and 5) to expose gaps in current understanding and knowledge. We
117 considered that the sixth indication, to conduct a scoping review as a precursor to conducting a

118 systematic review, would depend on our findings and the more focused questions those findings
119 would generate.

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

123 **Eligibility Criteria**

124 Studies were included if they focused on adults with IDD and had demographic
125 information about race and/or ethnicity. Only studies in English conducted in the United States
126 that were published after January 1, 2000, were included. Studies were excluded if: participants
127 were limited to children or adolescents < 18 years of age, or if information about adults 18 years
128 of age could not be separated from the information about children/adolescents; the studies
129 addressed only disabilities other than IDD; there was no race/ethnicity data; the studies were
130 conducted in countries other than the U.S.; or if no health-related research was conducted or
131 discussed. Reviews, systematic reviews, meta-analyses, case reports, opinion pieces, conference
132 abstracts, dissertations, and non-scholarly publications were also excluded.

133 **Search Strategy**

134 A medical librarian (CLH) searched the following databases for publications addressing
135 IDD and race/ethnicity: Ovid/MEDLINE; Wiley/Cochrane Library; Elsevier/Embase;
136 Elsevier/Scopus; Clarivate/Web of Science (WOS); EBSCO/ Cumulative Index of Nursing and
137 Allied Health Literature (CINAHL); EBSCO/PsycInfo; and ClinicalTrials.gov. Publications were
138 limited to those published between January 1, 2000 to March 26, 2019 (the date the searches
139 were completed). An English language filter was applied to all the searches. The search strategy

140 used in Ovid/MEDLINE, which was adapted for use in the other databases, is available in
141 Appendix A.

142 **Study Selection**

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

148 Two teams of screeners (TC-J; JE/SS/LKL) independently screened all titles and abstracts of
149 retrieved references for relevance to our questions. Disagreements were resolved by consultation
150 with one of three third reviewers (MSL, JSA, or HJW). Using the detailed inclusion/exclusion
151 criteria outlined above, the full texts of those publications selected during the title/abstract phase
152 were then similarly independently screened by two teams (TC-J; SS/LKL). Disagreements were
153 resolved by consultation with one of the three third reviewers (MSL, JSA, or HJW).

154 **Data Extraction**

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

163

Results

164

165

166

167

168

169

170

171

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.

172

Study Methodology & Geographic Distribution

173

174

175

176

177

178

179

180

181

182

183

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 & Haverkamp (2014) both analyzed a national survey specific to the IDD population called the National Core Indicators.

184

185

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

186 Deficit Hyperactivity Disorder (ADHD) examined smoking behaviors (Covey et al., 2010) and
187 ADHD symptoms among college students (Lee, Oakland, Jackson & Glutting, 2008). Survey
188 data were gathered from caregivers and parents/guardians through in-person interviews (Blacher
189 & McIntyre, 2006) and by telephone (Shattuck, Wagner, Narendorf, Sterzing & Hensley, 2011).
190 Magana, Seltzer & Krauss (2002) completed interviews with Puerto Rican adults with I.D. and
191 their mothers and analyzed results quantitatively. Jones et al. (2018) analyzed medical records of
192 pregnant African American women's self-reported behaviors with ADHD. Knoll, Janal, &
193 Khocht (2009) evaluated dental x-rays of adults with Down Syndrome. Lee, Clark, Kollins,
194 McClemon & Fuemmeler (2015) completed an analysis of the Add Health dataset, which
195 included individuals with ADHD.

196 Two studies analyzed data from observations. Latina mothers of individuals with Autism
197 Spectrum Disorder (ASD) were asked to collect behavioral information using an evaluation tool,
198 which was analyzed by Magana & Smith (2013). Horovitz, Matson, Hattier, Tureck & Bamburg
199 (2013) evaluated adults' behaviors with I.D. using an observational tool completed by
200 professionals.

201 Seven studies used qualitative approaches, which included interviews, focus groups, and
202 Photovoice methodology. Bogenschutz (2014) completed interviews with immigrants and
203 refugees with IDD. Terhune (2005) conducted interviews with African American caregivers of
204 individuals with D.D. Waite & Ramsay (2010) completed interviews with ethnically diverse
205 women with ADHD. Baker, Miller, Dang, Chiem-Seng & Hansen (2010) completed focus
206 groups with Southeast Asian caregivers of individuals with D.D. Lightfoot & Williams (2009)
207 completed focus groups with self-advocates and domestic violence providers. Jurkowski &

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

210 Twenty studies were based in a finite geographic area (one city or one state). Among
211 these, eight were based in California (Baker et al., 2010; Blacher & McIntyre, 2006; Harrington
212 & Kang, 2008; Harrington & Kang, 2010; Harrington & Kang, 2016; Kang & Harrington, 2008;
213 Leigh et al., 2016; Woo, 2017). Four articles evaluated health outcomes specific to one state or
214 city in the Midwest (Bell, Jackson & Bell, 2015; Covey et al., 2010; Jurkowski & Paul-Ward,
215 2007; Jurkowski et al., 2009). Four studies were in states on the east coast (Bogenschutz, 2014;
216 Jones et al., 2018; Knoll, Janal & Khocht, 2008; Sohler, et al, 2009), and four studies were set in
217 southern states (Horovitz et al., 2013; Nunez-Wallace et al., 2010; Parish et al., 2013, Terhune,
218 et al, 2005). Seven articles included multiple states or were regional (Li et al., 2017; Magana et
219 al., 2002; Magana & Smith, 2013; Patel et al., 2016; Scott & Haverkamp, 2014; Stancliffe &
220 Lakin, 2006; Waite & Ramsay, 2010). Eight articles had a national focus (Baloch & Jennings,
221 2019; Bershinsky et al., 2014; Johansen et al., 2015; Lee et al., 2008; Lee et al., 2015; Lightfoot
222 & Williams, 2008; Magana et al., 2016; Shattuck et al., 2011).

223 **Data Sources**

224 Considering the disability rights movement and the "nothing about us without us"
225 principle in disability activism, we identified the primary source for the research data to clarify if
226 people with IDD reported directly regarding their health. Twelve of the articles included data
227 collection directly with individuals with IDD. Among the quantitative articles that sourced data
228 directly from adults with IDD (N=7), four articles (Covey et al., 2010; Jones et al., 2018; Lee et
229 al., 2008; Lee et al., 2015) had a specific focus on adults with ADHD, with the remaining three
230 including people with IDD broadly (Bershinsky et al., 2014; Magana et al., 2002; Scott &

231 Havercamp, 2014). Adults with IDD were also directly involved in data collection in qualitative
232 studies (N=5). Four qualitative articles (Bogenschutz, 2014; Jurkowski & Paul-Ward, 2007;
233 Jurkowski et al., 2009; Lightfoot & Williams, 2008) included adults with IDD, and one article
234 specifically focused on women with ADHD (Waite & Ramsay, 2010). Five articles obtained data
235 directly from caregivers of those with IDD (Baker et al., 2010; Blacher & McIntyre, 2006;
236 Magana & Smith, 2013; Shattuck et al., 2011; Terhune, 2005). The remaining sixteen articles
237 completed secondary data analysis of service system data, including health records and social
238 services.

239 **Disparities Related to Race or Ethnicity**

240 Across a majority (n=33) of the studies, there was some form of disparity reported related
241 to race or ethnicity. Disparities by race and ethnicity were noted in service utilization, access to
242 care, oral health, mental health, social or behavioral outcomes, and culturally responsive
243 approaches to providing care/support. See Table 1 for a summary of study results by outcome of
244 focus. Two articles were found not to have a disparity-specific outcome related to race or
245 ethnicity. Bershadsky et al. (2014) used the national NCI data set and initially found differences
246 in getting preventive care by race/ethnicity, with non-Hispanic Whites accessing more preventive
247 care services. After controlling for other demographic variables, the racial/ethnic disparity was
248 no longer statistically significant. Lightfoot & Williams (2008) focused on identifying research
249 strategies for people of color with disabilities who have been victims of violence. Their
250 conclusions suggested approaches on conducting research with this population, highlighting the
251 importance of including people of color with disabilities throughout all research stages.

252 Seven of the articles focused on one race or ethnicity. Among these, four articles were
253 solely focused on individuals who were African American (Bell et al., 2015; Jones et al., 2018;

254 Knoll et al., 2008; Terhune, 2005), one focused on families who spoke Hmong-Mien (Baker et
255 al., 2010), one focused on Mexican Americans (Jurkowski & Paul-Ward, 2007) with I.D., and
256 one focused on Latinos with I.D. (Jurkowski et al., 2009). Bell et al. (2015) found that African
257 American adults diagnosed with IDD in childhood were more likely to be misdiagnosed in
258 adulthood with psychiatric issues. Jones et al. (2018) looked at the relationship between ADHD
259 symptoms, depression, and quality of life among pregnant African American women. African
260 American women with ADHD were more likely to have depression and have a lower quality of
261 life than those adults without ADHD. Knoll et al. (2008) looked at the prevalence of
262 periodontitis among African American individuals with Down Syndrome and found they had
263 higher rates of gum disease than those without Down Syndrome. Terhune (2005) listened to the
264 perspectives of low-income African American caregivers of adults with IDD regarding service
265 use. In Terhune's study, African American caregivers who identified with secular worldviews
266 were more likely to use formal disability services compared to caregivers with a spiritual
267 worldview. Those who identified as having spiritual worldviews were more likely to report using
268 informal support. Terhune also identified the need to reframe disability services outside of the
269 medical model.

270 Baker et al. (2010) conducted a qualitative community-based participatory research
271 project that addressed the understanding of developmental disability (D.D.) and disability service
272 systems among Hmong-Mien families. Baker et al. (2010) found that Hmong-Mien caregivers
273 and providers for individuals with D.D. noted a lack of trust in disability service systems.
274 Jurkowski & Paul-Ward (2007) found that being a Mexican American with an I.D. born in the
275 U.S. meant that those individuals were more likely to get health services as compared to

276 Mexican-born Mexican Americans with I.D. Latinos with I.D. wanted health services to be more
277 holistic and inclusive of mental health and social life (Jurkowski et al., 2009).

278 The remaining twenty-eight articles compared more than one racial or ethnic group.
279 Among these, seven were focused on comparing one group to their White counterparts. Amid the
280 seven comparing one group to their White counterparts, three (Horovitz et al., 2012; Lee et al.,
281 2008; Parish et al., 2013) compared African Americans to Whites, three articles (Blacher et al.,
282 2006; Magana et al., 2002; Magana & Smith, 2013) compared Latinos to Whites, and one article
283 (Woo, 2017) compared Asians to Whites. White adults with I.D. were more likely to have
284 challenging behaviors compared to African American individuals with I.D. (Horovitz et al.,
285 2012). African American college students were more likely to report ADHD symptoms as
286 compared to White students (Lee et al., 2008). Parish and colleagues (2013) identified that White
287 women with I.D. were more likely to receive a mammogram, with rates 3-5 times higher, than
288 African American women with I.D. Blacher et al. (2006) found that Latino mothers of adults
289 with I.D. had both higher depressive symptoms and positive feelings about their child compared
290 to White mothers of adults with I.D. Magana & Smith (2013) found that Latino individuals with
291 ASD had fewer repetitive behaviors reported by their mothers on the Autism Diagnostic
292 Interview-Revised compared to Whites and concluded that future research should look at the
293 cultural relevance of these assessment questions. Magana et al. (2002) found that Puerto Rican
294 adults with I.D. and their families had more unmet service needs as compared to White adults
295 with I.D. Woo (2017) identified that Asian Americans with I.D. or other mental health conditions
296 were less likely to use mental health services compared to their Non-Hispanic White
297 counterparts.

298 Twenty-one articles compared three or more racial or ethnic groups. Two studies pointed
299 to the critical need to develop culturally appropriate education to encourage the use of services
300 among families who are immigrants or refugees (Baker et al., 2010; Bogenschutz et al., 2014).
301 Women from ethnic and minority backgrounds, including African American, Hispanic,
302 American Indian, and Asian, and with ADHD advocated for more culturally and gender-relevant
303 care (Waite & Ramsay, 2010). When comparing diagnoses of incarcerated populations, African
304 Americans were more likely to have cognitive disabilities, and Whites had a higher prevalence of
305 psychosocial disabilities (Baloch & Jennings, 2019). White males with more severe ADHD
306 symptoms were more likely to smoke than non-White males (Lee et al., 2015). In evaluating a
307 smoking cessation medication intervention, non-White participants with ADHD had more
308 success with quitting smoking (Covey et al., 2010). African American, Hispanic, and Asian
309 individuals with ADHD had lower rates of use of ADHD medication, which may be due to a lack
310 of a usual source of care (Johansen et al., 2015). Individuals with ADHD from minoritized racial
311 or ethnic groups were less likely to start or maintain the use of medications (Li et al., 2017).
312 African American adults with D.D. were less likely to adhere to diabetes medication compared to
313 White adults with D.D. (Patel et al., 2016).

314 Five studies involved a secondary analysis of disability service system data from
315 California examining differences among racial/ethnic groups. In California, racial/ethnic
316 minoritized individuals with IDD received fewer services than Whites with IDD (Harrington &
317 Kang, 2008; Harrington & Kang, 2010, Kang & Harrington, 2008). Also, in California,
318 racial/ethnic minority groups were more likely to receive personal care services than Whites but
319 received fewer personal care service hours approved than Whites (Harrington & Kang, 2010).

320 An analysis of disability service system data also identified that Whites with an ASD received
321 more services than those from racial or ethnic minority groups (Leigh et al., 2016).

322 Studies of secondary health data reveal suboptimal health outcomes for people of color
323 with disabilities. In evaluating health data from twenty-five states, adults with IDD who also
324 identified as being a member of a minoritized racial/ethnic group were less likely to have visited
325 a dentist or general practitioner or to receive a flu shot (Scott & Havercamp, 2014). African
326 American women with IDD were more likely to receive a mammogram than other racial/ethnic
327 groups, and Hispanic people with IDD were less likely to participate in cancer screenings than
328 Whites (Scott & Havercamp, 2014). An analysis of post-high school outcomes among
329 individuals with ASD found that African American young adults with ASD were less likely to
330 get speech therapy, case management, mental health services, and medical evaluations compared
331 to their White peers (Shattuck et al., 2011). Finally, when a conservator was in place to make
332 medical decisions for adults with profound I.D., the race/ethnicity of the individual with I.D. was
333 not related to consent for treatment. Still, African American conservators were less likely to
334 approve treatment than White conservators (Nunez-Wallace et al., 2010). Latino and Black
335 adults with IDD had poorer health outcomes compared to White individuals with IDD (Magana
336 et al., 2016). Black and Hispanic adults with IDD were more likely to be overweight or obese
337 compared to White adults with IDD (Magana et al., 2016; Sohler et al., 2009). In other research,
338 Whites with IDD had a higher quality of life evaluation scores than African Americans with IDD
339 (Stancliffe & Lakin, 2006).

340 **Insert Table 1 Here.**

341 **Discussion**

342 Researchers in the disability research and advocacy world have called for an
343 intersectional approach to understanding the experience of disability (Banks, 2018; Warner &
344 Brown, 2011). Our findings point to the importance of concentrated funding supporting equity-
345 focused research identifying health promotion gaps for minoritized racial/ethnic groups with
346 IDD. A significant number of diverse policies and funding for IDD services exist state-by-state;
347 state-focused research can highlight areas for improving equity, particularly in service
348 utilization, which can help address the social determinants of health and facilitate access to
349 health-promoting activities (e.g., community inclusion). For example, Harrington and colleagues
350 (2008) found that racial/ethnic minoritized people with IDD were less likely to receive services,
351 and services were funded at lower rates than White people with IDD in California. Half of the
352 articles that focused exclusively on California were from Harrington's research team, which had
353 received a grant from the National Institute for Disability and Rehabilitation Research (currently
354 National Institute on Disability, Independent Living, and Rehabilitation Research) to explore
355 service utilization and expenditures in California, with the explicit goal of examining "the
356 number and types of individuals with IDD living at home or in the community in California in
357 terms of their predisposing socio-demographic characteristics (e.g., age, gender, race/ethnicity,
358 language)" (National Rehabilitation and Information Center, 2005). Their research program
359 follows the National Center on Cultural Competence's articulation of disparities in service and
360 supports as disparities in availability, accessibility, acceptability, quality, and utilization
361 (National Center for Cultural Competence, 2020). Intentional research by race/ethnicity serves to
362 examine the distribution of disability resources in California, which is known to be one of the
363 lowest in terms of expenditures for these resources (Tanis et al., 2020).

364 Additionally, our findings highlight the importance of early access to health care as a
365 means to prevent comorbid conditions and premature death. Adults with IDD experience more
366 comorbidities and shorter lifespans as compared to the general population (Cooper et al. 2015),
367 yet access to health care among adults with IDD remains low. Many racial/ethnic minority
368 groups with IDD do not have a regular care provider, which can impact adherence to health care,
369 such as taking prescribed medication (Johansen et al., 2015). Adults with IDD also have higher
370 rates of comorbid conditions that could have been prevented or ameliorated if there had been
371 access to care (Reichard, Stolzle & Fox, 2011; Lauer & McCallion, 2015; Havercamp, Scandlin
372 & Roth, 2004).

373 This scoping review highlights the missed opportunities for collecting self-reported data
374 from people with IDD. Qualitative research methods play an important role in incorporating
375 individuals' voices from underrepresented populations such as individuals with IDD. These
376 methods may enhance a lack of data from smaller populations such as American Indian/Alaska
377 Natives, which are frequently omitted from large data sets due to incomplete data. Incomplete
378 data may result from the U.S. Federal government's inattention to supporting data sovereignty
379 among tribes, which could generate more complete data sets (Carroll, Rodriquez-Lonebear &
380 Martinez, 2019). Qualitative and community-based approaches have provided insight into the
381 lives of individuals with IDD, using methods such as Photovoice (Williamson, van Heuman &
382 Schwartz, 2019). Research has yet to increase participation from individuals with IDD as
383 research participants (Caldwell, 2013; Beail & Williams, 2014). Innovative approaches that are
384 inclusive of individuals with IDD must be considered. Williamson, van Heumen & Schwartz
385 (2020) utilized Photovoice, a method in which individuals use photography to share their stories
386 about an issue, thus maximizing the strengths of non-university-based co-researchers with IDD.

387 The authors acknowledge the significant amounts of time required for this approach, including
388 educating Institutional Review Boards about research with people with IDD as engaged research
389 participants. The authors recognize the opportunities for building innovative knowledge about,
390 with, and for people with IDD when researchers are open to novel methodologies. Qualitative
391 and participatory methodologies can also fill a significant gap in culturally responsive research
392 and services.

393 **Conclusions**

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

406
407
408
409
410
411
412
413

414 **References**

- 415 American Association of Intellectual and Developmental Disabilities. (2008). *Frequently*
416 *Asked Questions on Intellectual Disability and the AAIDD Definition.*
417 [https://www.aaidd.org/docs/defaultsource/sisdocs/aaiddfaqonid_template.pdf?sfvrsn=a](https://www.aaidd.org/docs/defaultsource/sisdocs/aaiddfaqonid_template.pdf?sfvrsn=a3a874_2)
418 [3a874_2](https://www.aaidd.org/docs/defaultsource/sisdocs/aaiddfaqonid_template.pdf?sfvrsn=a3a874_2)
- 419 Annamma, S.A., Connor, D. & Ferri, B. (2013). Dis/ability critical race studies (DisCrit):
420 theorizing at the intersections of race and dis/ability. *Race Ethnicity and Education,*
421 *16(1), 1-31, doi: https://doi.org/10.1080/13613324.2012.730511*
- 422 Baker, D. L., Miller, E., Dang, M. T., Yaangh, C. S., & Hansen, R. L. (2010). Developing
423 culturally responsive approaches with Southeast Asian American families experiencing
424 developmental disabilities. *Pediatrics, 126(Supplement 3), S146-S150. doi:*
425 <https://doi.org/10.1542/peds.2010-1466I>
- 426 Bagenstos, S. R. (2015). The disability cliff. *Democracy, 25, 55-67.* Retrieved from
427 <https://repository.law.umich.edu/articles/1722/>
- 428 Baloch, N. A., & Jennings, W. G. (2019). A preliminary investigation of the intersection of race
429 and disabilities among inmates in the U.S. State Prison System. *International Journal of*
430 *Offender Therapy and Comparative Criminology, 63(4), 597-609. doi:*
431 <https://doi.org/10.1177/0306624X18805599>
- 432 Banks, J. (2018). Invisible man: examining the intersectionality of disability, race, and gender in
433 an urban community. *Disability & Society, 33(6), 894-908. doi:*
434 <https://doi.org/10.1080/09687599.2018.1456912>
- 435 Beail, N. & Williams, K. (2014). Using Qualitative Methods in Research with People Who Have
436 Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities, 27(2),*

- 437 85-96. doi: <https://doi.org/10.1111/jar.12088>
- 438 Bell, C. C., Jackson, W. M., & Bell, B. H. (2015). Misdiagnosis of African-Americans with
439 psychiatric issues—part I. *Journal of the National Medical Association, 107*(3), 25-34.
440 doi: [https://doi.org/10.1016/S0027-9684\(15\)30048-1](https://doi.org/10.1016/S0027-9684(15)30048-1)
- 441 Bershadsky, J., Hiersteiner, D., Fay, M. L., & Bradley, V. (2014). Race/ethnicity and the use of
442 preventive health care among adults with intellectual and developmental disabilities.
443 *Medical Care, 52*(10 Suppl 3), S25-S31. doi: [https://doi.org/](https://doi.org/10.1097/MLR.0000000000000130)
444 [10.1097/MLR.0000000000000130](https://doi.org/10.1097/MLR.0000000000000130)
- 445 Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioural disorders in young
446 adults with intellectual disability: Cultural differences in family impact. *Journal of*
447 *Intellectual Disability Research, 50*(3), 184-198. doi:
448 [https://doi.org/ 10.1111/j.1365-2788.2005.00768.x](https://doi.org/10.1111/j.1365-2788.2005.00768.x)
- 449 Bogenschutz, M. (2014). " We Find a Way": Challenges and Facilitators for Health Care Access
450 Among Immigrants and Refugees With Intellectual and Developmental Disabilities.
451 *Medical Care, 52*(10 Suppl 3), S64-S70. doi:
452 <https://doi.org/10.1097/MLR.0000000000000140>
- 453 Bonardi, A., Krahn, G., Morris, A. & the National Workgroup on State and Local Health
454 Data. (2019). *Enriching our Knowledge: State and Local Data to Inform Health*
455 *Surveillance of the Population with Intellectual and Developmental Disabilities.*
456 Washington DC: Administration on Intellectual and Developmental Disabilities.
- 457 Braddock, D., Hemp, R., Rizzolo, M.C., Tanis, E.S., Haffer, L., & Wu, J. (2015). *The State of*
458 *the States in Intellectual and Developmental Disabilities: Emerging from the Great*
459 *Recession.* Washington, DC: American Association on Intellectual and Developmental

- 460 Disabilities (AAIDD).
- 461 Caldwell, Kate. (2013). Dyadic interviewing: a technique valuing interdependence in interviews
462 with individuals with intellectual disabilities. *Qualitative Research*, 14(4), 488-507. doi:
463 <https://doi.org/10.1177/1468794113490718>
- 464 Charlton, J.I. (1998). *Nothing About Us Without Us: Disability Oppression and Empowerment*.
465 University of California Press. Retrieved March 5, 2021, from
466 <http://www.jstor.org/stable/10.1525/j.ctt1pnqn9.1>
- 467 Carroll, S.R., Rodriguez-Lonebear, D., & Martinez, A. (2019). Indigenous Data Governance:
468 Strategies from United States Native Nations. *Data Science Journal*, 18(1), 1–15. doi:
469 <https://doi.org/10.5334/dsj-2019-031>
- 470 Center for Disease Control and Prevention. (2020). *Disability and Health Data System*
471 *(DHDS)*. Retrieved January 16, 2021, from <http://dhds.cdc.gov>
- 472 Center for Disease Control and Prevention. (2021). *National Health Interview Survey*.
473 Retrieved March 4, 2021, from <https://www.cdc.gov/nchs/nhis/index.htm>
- 474 Cooper, S.A., McLean, G., Guthrie, B., McConnachie, A., Mercer, S., Sullivan, F. & Morrison,
475 J. (2012). Multiple physical and mental health comorbidity in adults with intellectual
476 disabilities: population-based cross-sectional analysis. *BMC Family Practice*, 16(110), 2
477 11. doi: <https://doi.org/10.1186/s12875-015-0329-3>
- 478 Covey, L. S., Hu, M. C., Winhusen, T., Weissman, J., Berlin, I., & Nunes, E. V. (2010). OROS
479 methylphenidate or placebo for adult smokers with attention deficit hyperactivity
480 disorder: racial/ethnic differences. *Drug and alcohol dependence*, 110(1-2), 156-159. doi:
481 <https://doi.org/10.1016/j.drugalcdep.2012.01.019>
- 482 Courtney-Long, E.A., Romano, S.D., Carroll, D.D. & Fox, M.H. (2017). Socioeconomic

- 483 Factors at the Intersection of Race and Ethnicity Influencing Health Risks for People
484 with Disabilities. *J Racial Ethn Health Disparities*, 4(2), 213-222. doi: [https://doi.org/
485 0.1007/s40615-016-0220-5](https://doi.org/0.1007/s40615-016-0220-5)
- 486 Frederick, A. & Shifrer, D. (2018). Race and Disability: From Analogy to Intersectionality.
487 *Sociology of Race and Ethnicity*, 5(2), 200-214. doi:
488 <https://doi.org/10.1177/2332649218783480>
- 489 Georgetown University Center for Child Health & Human Development. National Center for
490 Cultural Competence. Retrieved from
491 <https://nccc.georgetown.edu/resources/disparities-in-idd.php>
- 492 Goering, S. (2015). Rethinking disability: the social model of disability and chronic disease.
493 *Curr Rev Musculoskelet Med*, 8(2), 134-8. doi: [https://doi.org/10.1007/s12178-015-
9273-z](https://doi.org/10.1007/s12178-015-
494 9273-z)
- 495 Hankivsky, O. (2012). Women's health, men's health, and gender and health: Implications of
496 intersectionality. *Social Science & Medicine*, 72, 1712-1720. doi:
497 <https://doi.org/10.1016/j.socscimed.2011.11.029>
- 498 Harrington, C., & Kang, T. (2008). Disparities in service utilization and expenditures for
499 individuals with developmental disabilities. *Disability and Health Journal*, 1(4), 184-195.
500 doi: <https://doi.org/10.1016/j.dhjo.2008.05.004>
- 501 Harrington, C., & Kang, T. (2008). Disparities in service utilization and expenditures for
502 individuals with developmental disabilities. *Disability and Health Journal*, 1(4), 184-195.
503 doi: <https://doi.org/10.1016/j.dhjo.2008.05.004>
- 504 Harrington, C., & Kang, T. (2010). Personal care services utilization by individuals with

- 505 developmental disabilities. *Family Relations*, 59(2), 136-151. doi:
506 <https://doi.org/10.1111/j.1741-3729.2010.00591.x>
- 507 Havercamp, S., Scandlin, D. & Roth, M. (2004). Health disparities among adults with
508 developmental disabilities, adults with other disabilities, and adults not reporting
509 disability in North Carolina. *Public Health Reports*, 119, 418–426. doi:
510 <https://doi.org/10.1016/j.phr.2004.05.006>
- 511 Havercamp S.M. & Scott, H.M. (2015). National health surveillance of adults with
512 disabilities, adults with intellectual and developmental disabilities, and adults with no
513 disabilities. *Disability and Health Journal*, 8(2), 165-72. doi:
514 <https://doi.org/10.1016/j.dhjo.2014.11.002>
- 515 Horovitz, M., Matson, J. L., Hattier, M. A., Tureck, K., & Bamburg, J. W. (2013). Challenging
516 behaviors in adults with intellectual disability: The effects of race and autism spectrum
517 disorders. *Journal of Mental Health Research in Intellectual Disabilities*, 6(1), 1-13. doi:
518 <https://doi.org/10.1080/19315864.2011.605989>
- 519 Human Services Research Institute and National Association of State Directors of
520 Developmental Disabilities Services. National Core Indicators. Retrieved from
521 <https://www.nationalcoreindicators.org/>
- 522 Johansen, M. E., Matic, K., & McAlearney, A. S. (2015). Attention deficit hyperactivity disorder
523 medication use among teens and young adults. *Journal of Adolescent Health*, 57(2), 192
524 197. doi: <https://doi.org/10.1016/j.jadohealth.2015.04.009>
- 525 Jones, H. A., Eddy, L. D., Bouchtein, E., Parks, A. M., Green, T. L., Karjane, N. W., & Svikis,

- 526 D. S. (2018). Attention-Deficit/Hyperactivity disorder symptoms, depression risk, and
527 quality of life in black pregnant women. *Journal of Women's Health, 27*(10), 1263-1270.
528 doi: <https://doi.org/10.1089/jwh.2017.6547>
- 529 Jurkowski, J. M., & Paul-Ward, A. (2007). Photovoice with vulnerable populations: Addressing
530 disparities in health promotion among people with intellectual disabilities. *Health
531 Promotion Practice, 8*(4), 358-365. doi: <https://doi.org/10.1177/1524839906292181>
- 532 Jurkowski, J. M., Rivera, Y., & Hammel, J. (2009). Health perceptions of Latinos with
533 intellectual disabilities: The results of a qualitative pilot study. *Health Promotion
534 Practice, 10*(1), 144-155. doi: <https://doi.org/10.1177/1524839907309045>
- 535 Kang, T., & Harrington, C. (2008). Variation in types of service use and expenditures for
536 individuals with developmental disabilities. *Disability and Health Journal, 1*(1), 30-41.
537 doi: <https://doi.org/10.1016/j.dhjo.2007.11.008>
- 538 Krahn, G.L. & Fox, M.H. (2014). Health Disparities of Adults with Intellectual Disabilities:
539 What Do We Know? What Do We Do? *Appl Res Intellect Disabil, 27*(5), 431–446. doi:
540 <https://doi.org/10.1111/jar.12067>
- 541 Krahn, G.L., Walker, D.K. & Correa-De-Araujo. (2015). Persons with Disabilities as an
542 Unrecognized Health Disparity Population. *Am J Public Health, 105*, 198–S206. doi:
543 <https://doi.org/10.2105/AJPH.2014.302182>
- 544 Knoll, S., Janal, M., & Khocht, A. (2008). Radiographic assessment of periodontitis in African
545 Americans with Down syndrome. *Journal of the International Academy of
546 Periodontology, 10*(1), 16-21.
- 547 Kuntz, E. M., & Carter, E. W. (2019). Review of interventions supporting secondary students

- 548 with intellectual disability in general education classes. *Research and Practice for*
549 *Persons with Severe Disabilities*, 44(2), 103-121. doi:
550 <https://doi.org/10.1177/1540796919847483>
- 551 Lauer, E. & McCallion, P. (2015). Mortality of people with intellectual and developmental
552 disabilities from select U.S. state disability service systems and medical claims data.
553 *Journal of Applied Research in Intellectual Disabilities*, 28, 394–405. doi:
554 <https://doi.org/10.1111/jar.12191>
- 555 Lee, C. T., Clark, T. T., Kollins, S. H., McClernon, F. J., & Fuemmeler, B. F. (2015). Attention
556 Deficit Hyperactivity Disorder symptoms and smoking trajectories: *Race and gender*
557 *differences. Drug and alcohol dependence*, 148, 180-187. doi:
558 <https://doi.org/10.1016/j.drugalcdep.2015.01.002>
- 559 Lee, D. H., Oakland, T., Jackson, G., & Glutting, J. (2008). Estimated prevalence of attention
560 deficit/hyperactivity disorder symptoms among college freshmen: Gender, race, and rater
561 effects. *Journal of Learning Disabilities*, 41(4), 371-384. doi:
562 <https://doi.org/10.1177/0022219407311748>
- 563 Leigh, J. P., Grosse, S. D., Cassady, D., Melnikow, J., & Hertz-Picciotto, I. (2016). Spending by
564 California's Department of Developmental Services for persons with autism across
565 demographic and expenditure categories. *PLoS One*, 11(3), e0151970. doi:
566 <https://doi.org/10.1371/journal.pone.0151970>
- 567 Li, Y., Liu, W., Zhu, Y., Liu, X., & Winterstein, A. G. (2017). Determinants of Pharmacological
568 Treatment Initiation and Persistence in Publicly Insured Adults With Attention
569 Deficit/Hyperactivity Disorder. *Journal of clinical psychopharmacology*, 37(5), 546-554.
570 doi: <https://doi.org/10.1097/jcp.0000000000000759>

- 571 Lightfoot, E., & Williams, O. (2009). Critical issues in researching domestic violence among
572 people of color with disabilities. *Journal of Aggression, Maltreatment & Trauma, 18*(2),
573 200-219. doi: <https://doi.org/10.1080/10926770802675684>
- 574 Magaña, S., Seltzer, M. M., & Krauss, M. W. (2002). Service utilization patterns of adults with
575 intellectual disabilities: A comparison of Puerto Rican and non-Latino White families.
576 *Journal of Gerontological Social Work, 37*(3-4), 65-86. doi:
577 https://doi.org/10.1300/J083v37n03_06
- 578 Magaña, S., & Smith, L. E. (2013). The use of the Autism Diagnostic Interview-Revised with a
579 Latino population of adolescents and adults with autism. *Journal of autism and*
580 *developmental disorders, 43*(5), 1098-1105. doi: <https://doi.org/10.1007/s10803-012->
581 1652-3
- 582 Magaña, S., Parish, S., Morales, M. A., Li, H., & Fujiura, G. (2016). Racial and ethnic health
583 disparities among people with intellectual and developmental disabilities. *Intellectual and*
584 *Developmental Disabilities, 54*(3), 161-172. doi: <https://doi.org/10.1352/1934-9556->
585 54.3.161
- 586 Mitra, S. (2015). Data revolution for disability-inclusive development. *The Lancet Global*
587 *Health, 1*(4), e178-e179. doi: [https://doi.org/10.1016/S2214-109X\(13\)70016-0](https://doi.org/10.1016/S2214-109X(13)70016-0)
- 588 Morgan, P. L., Farkas, G., Hillemeier, M. M., & Maczuga, S. (2017). Replicated evidence of
589 racial and ethnic disparities in disability identification in U.S. schools. *Educational*
590 *Researcher, 46*(6), 305-322. doi: <https://doi.org/10.3102/0013189X17726282>
- 591 Munn, Z., Peters, M.D.J, Stern, C., Tufanaru, C., McArthur, A., & Aromataris, E. (2018).

- 592 Systematic review or scoping review? Guidance for authors when choosing between
593 systematic or scoping review approach. *BMC Medical Research Methodology*, 18,
594 143. doi: <https://doi.org/10.1186/s12874-018-0611-x>
- 595 National Rehabilitation Information Center. (2005). *National Institute on Disability and*
596 *Rehabilitation Research Program Directory*.
597 <https://search.naric.com/research/pd/pdf/NIDRR2005.pdf>
- 598 Nehring W.M., Lindsey B. (2016) History of Health Care for People with Intellectual and
599 Developmental Disability. In: I.L. Rubin, J. Merrick, D.E. Greydanus & D.R. Patel
600 (Eds.), *Health Care for People with Intellectual and Developmental Disabilities across*
601 *the Lifespan*. Springer, Cham, [https://link.springer.com/chapter/10.1007/978-3-319-](https://link.springer.com/chapter/10.1007/978-3-319-18096-0_3)
602 [18096-0_3](https://link.springer.com/chapter/10.1007/978-3-319-18096-0_3)
- 603 Nunez-Wallace, K. R., Gill, C. E., Harrison, C. H., Taylor, H. M., & Charles, P. D. (2010).
604 Discordance in informed consent response on the basis of demographic factors: brief
605 report. *Intellectual and developmental disabilities*, 48(3), 175-179. doi:
606 <https://doi.org/10.1352/1944-7558-48.3.175>
- 607 Parish, S. L., Swaine, J. G., Son, E., & Luken, K. (2013). Receipt of mammography among
608 women with intellectual disabilities: medical record data indicate substantial disparities
609 for African American women. *Disability and Health Journal*, 6(1), 36-42. doi:
610 <https://doi.org/10.1016/j.dhjo.2012.08.004>
- 611 Patel, I., Erickson, S. R., Caldwell, C. H., Woolford, S. J., Bagozzi, R. P., Chang, J., &
612 Balkrishnan, R. (2016). Predictors of medication adherence and persistence in Medicaid
613 enrollees with developmental disabilities and type 2 diabetes. *Research in Social and*

- 614 *Administrative Pharmacy*, 12(4), 592-603. doi:
615 <https://doi.org/10.1016/j.sapharm.2015.09.008>
- 616 Reichard, Amanda, Stolzle, Hayley, and Fox, Michael. (2011). Health disparities among adults
617 with physical disabilities or cognitive limitations compared to individuals with no
618 disabilities in the United States. *Disability and Health Journal*, 4, 59–67. doi:
619 <https://doi.org/10.1016/j.dhjo.2010.05.003>
- 620 Residential Information Systems Project (2020). Home Page. Minneapolis: University of
621 Minnesota, RISP, Research and Training Center on Community Living, Institute on
622 Community Integration. Retrieved from: <https://risp.umn.edu>
- 623 Rembis, M., Kudlick, C. & Nielsen, K. (Eds.) (2018). *Disability and the History of Eugenics*.
624 Oxford University Press. doi: <https://doi.org/10.1093/oxfordhb/9780190234959.013.6>
- 625 Scott, H. M., & Havercamp, S. M. (2014). Race and health disparities in adults with intellectual
626 and developmental disabilities living in the United States. *Intellectual and developmental*
627 *disabilities*, 52(6), 409-418. doi: <https://doi.org/10.1352/1934-9556-52.6.409>
- 628 Shattuck, P. T., Wagner, M., Narendorf, S., Sterzing, P., & Hensley, M. (2011). Post-high school
629 service use among young adults with an autism spectrum disorder. *Archives of pediatrics*
630 *& adolescent medicine*, 165(2), 141-146. doi:
631 <https://doi.org/10.1001/archpediatrics.2010.279>
- 632 Sohler, N., Lubetkin, E., Levy, J., Soghomonian, C., & Rimmerman, A. (2009). Factors
633 associated with obesity and coronary heart disease in people with intellectual disabilities.
634 *Social Work in Health Care*, 48(1), 76-89. doi:
635 <https://doi.org/10.1080/00981380802451160>
- 636 Stancliffe, R. J., & Lakin, K. C. (2006). Minority status, consumer outcomes, and service inputs

- 637 in four states. *Mental retardation*, 44(3), 165-183. doi: <https://doi.org/10.1352/0047->
638 6765(2006)44[165:MSCOAS]2.0.CO;2
- 639 Tanis, E.S., Lulinski, A. & Wu, J., Braddock, D. & Hemp, R. (2020). The State of the States in
640 intellectual and Developmental Disabilities, Department of Psychiatry, University of
641 Colorado. www.stateofthestates.org
- 642 Terhune, P. S. (2005). African-American developmental disability discourses: Implications for
643 policy development. *Journal of Policy and Practice in Intellectual Disabilities*, 2(1), 18-
644 28. doi: <https://doi.org/10.1111/j.1741-1130.2005.00004.x>
- 645 Thomas, G. M., & Rothman, B. K. (2016). Keeping the backdoor to eugenics ajar?: Disability
646 and the future of prenatal screening. *AMA Journal of Ethics*, 18(4), 406-415. doi:
647 <https://doi.org/10.1001/journalofethics.2016.18.4.stas1-1604>
- 648 Tricco A.C., Lillie E., Zarin, W., O'Brien, K.K., Colquhoun, H., Levac, D. Moher, D., Peters,
649 M.D.J., et al. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR):
650 Checklist and Explanation. *Ann Intern Med*, 169(7), 467-473. doi:
651 <https://doi.org/10.7326/M18-0850>
- 652 Waite, R., & Tran, M. (2010). ADHD among a cohort of ethnic minority women. *Women &*
653 *Health*, 50(1), 71-87. doi: <https://doi.org/10.1080/03630241003601095>
- 654 Warner, D.F. & Brown, T.H. (2011). Understanding How Race/Ethnicity and Gender Define
655 Age-Trajectories of Disability: An Intersectionality Approach. *Soc Sci Med*, 72(8),
656 1236-1248. doi: <https://doi.org/10.1016/j.socscimed.2011.02.034>
- 657 Williamson, H. J., van Heumen, L., & Schwartz, A. E. (2020). Photovoice with Individuals

- 658 with Intellectual and/or Developmental Disabilities: Lessons Learned from Inclusive
659 Research Efforts. *Collaborations: A Journal of Community-based Research and*
660 *Practice*, 3(1), 8. doi: <https://doi.org/10.33596/coll.45>
- 661 Woo, B. K. (2017). Comparison of mental health service utilization by Asian Americans and
662 non-Hispanic Whites versus their cardiovascular care utilization. *Cureus*, 9(8), e1595.
663 doi: <https://doi.org/10.7759/cureus.1595>
- 664 Zablotsky, B., Black, L.I., Maenner, M.J., Schieve, L.A., Danielson, M.L., Bitsko, R.H.,
665 Blumberg, S.J., Kogan, M.D., & Boyle, C.A. (2019). Prevalence and Trends of
666 Developmental Disabilities among Children in the United States: 2009–2017.
667 *Pediatrics*, 144(4), e20190811. doi: <https://doi.org/10.1542/peds.2019-0811>

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

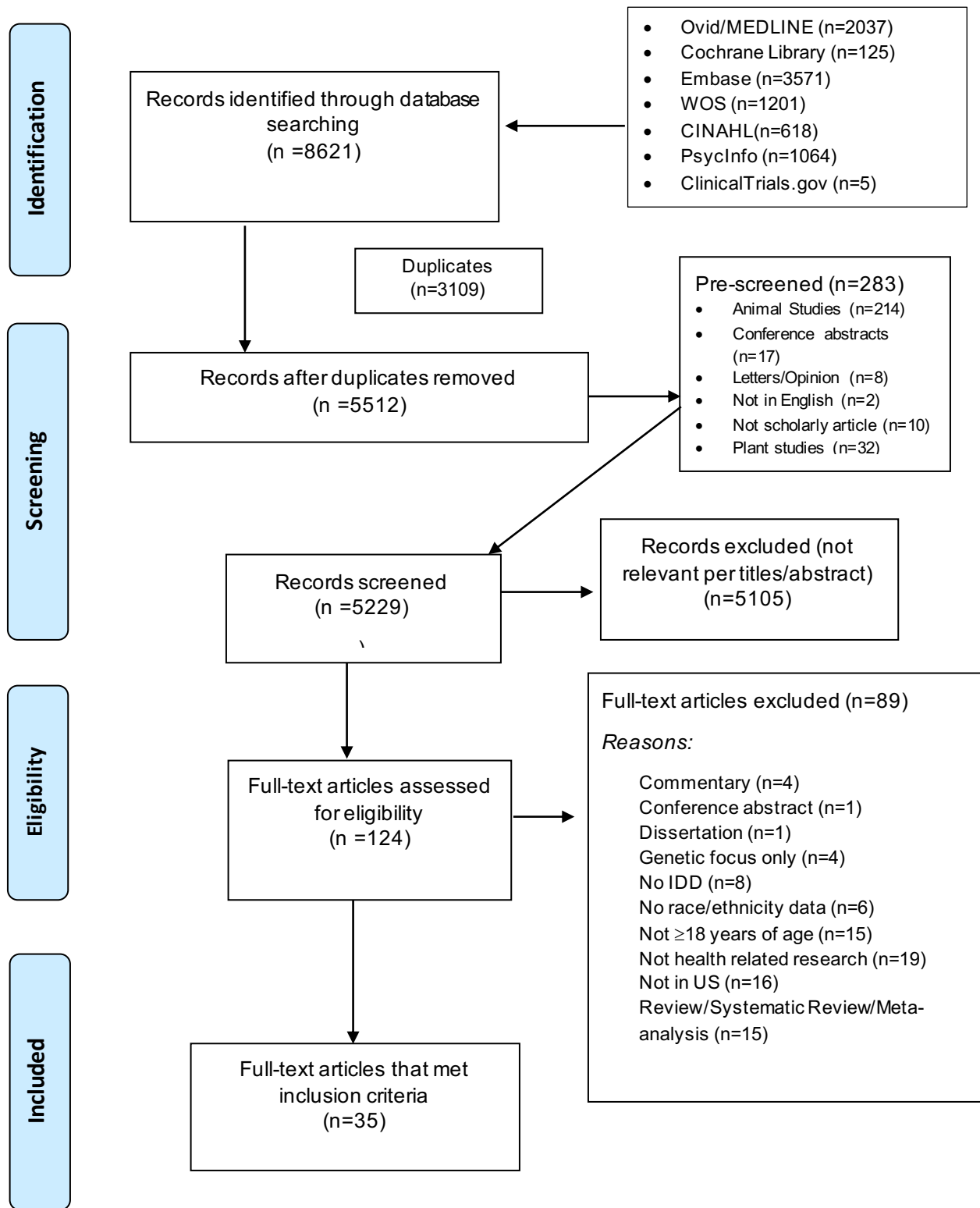


Table 1*Summary of Studies (N=35) Based on Race or Ethnic Analysis Scope and Outcome of Focus*

Author, Year	Race or Ethnic Analysis Scope				Outcome of Focus*				
	Disparity by Race or Ethnicity (n=33)	One Race or 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			

Author, Year	Race or Ethnic Analysis Scope				Outcome of Focus*				
	Disparity by Race or Ethnicity (n=33)	One Race or 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)
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		

Author, Year	Race or Ethnic Analysis Scope				Outcome of Focus*				
	Disparity by Race or Ethnicity (n=33)	One Race or 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)
Jurkowski & Paul-Ward, 2007	X	X			X	X			
Jurkowski et al., 2009	X			X		X	X		X
Kang & Harrington, 2008	X			X	X				
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

Author, Year	Race or Ethnic Analysis Scope				Outcome of Focus*				
	Disparity by Race or Ethnicity (n=33)	One Race or 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)
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

Author, Year	Race or Ethnic Analysis Scope				Outcome of Focus*				
	Disparity by Race or Ethnicity (n=33)	One Race or 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)
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		

Race or Ethnic Analysis Scope					Outcome of Focus*				
Author, Year	Disparity by Race or Ethnicity (n=33)	One Race or 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)

*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