



Listening to Black Californians with Disabilities

Black Californians with Disabilities Frequently Interact with the Health System While Tending to Their Health

Black Californians with disabilities are frequent users of the health care system. In the year prior to the survey, 94% of Black Californians with disabilities reported at least one visit with a doctor or health care provider, and 52% reported having five or more visits. More Black Californians with disabilities report receiving a routine check-up (80%), routine or preventive screenings (81%), and care or treatment for a chronic illness (57%) than those without with disabilities (74% check-up, 71% screening, 24% chronic illness).

Like other groups of Black Californians highlighted in this series, those with disabilities engage in a variety of activities to manage and improve their physical and mental health. Respondents with disabilities are significantly more likely to track indicators of personal health or symptoms (80%) – such as blood pressure, blood sugar, cholesterol, sleep patterns, or headaches – than those without disabilities (69%). Four in five Black Californians with disabilities report putting a “great deal” or “quite a bit” of effort into focusing on their mental health (80%) and are

actively trying to reduce stress (80%). Three in four put effort into praying or engaging in spiritual activity (75%) (Figure 1).

About the Study

In 2021, Black-owned research firm EVITARUS conducted the *Listening to Black Californians* study for CHCF. In 100 individual interviews,¹ 18 focus groups, and a statewide survey of 3,325 adult Black Californians,² participants described their attitudes toward their own health and their experiences with the health care system. This set of fact sheets highlights the health care experiences of specific groups within California’s Black population. This fact sheet was written by Linda Cummings, PhD.

About the Participants: Black Californians with Disabilities

In 2021, one in four California adults (25.4%) reported a disability, similar to the percentage of adults reporting disabilities nationwide (27%).³ Approximately one in five *Listening to Black Californians* survey respondents (19%) report having “a disability of any type (such as mobility, cognitive, visual or sensory).” Reports of disabilities among Black Californians rise markedly after age 55, with more than half of respondents (54%) age 55 or older reporting disabilities.

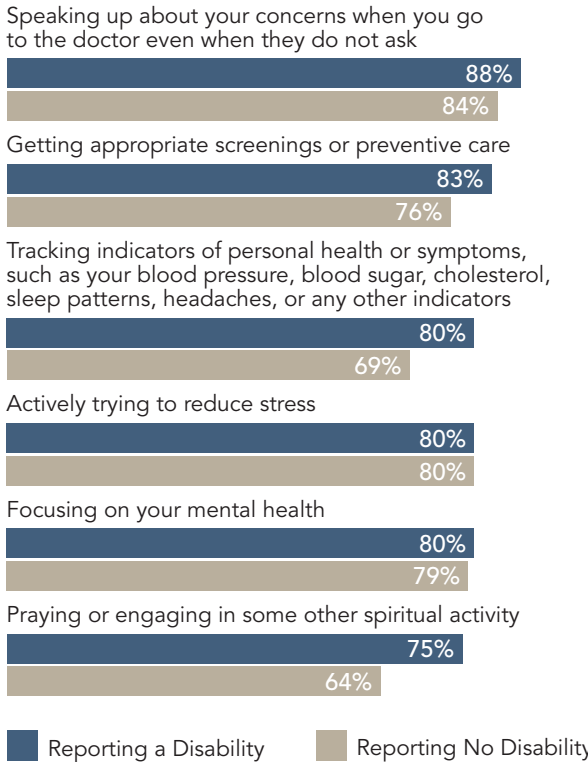
Two in five Black Californians with disabilities have incomes below 200% of the federal poverty level (FPL) (42%), compared to one in four (26%) of those without a disability. Black Californians with disabilities are more likely to be covered by Medi-Cal (30%) or Medicare (32%) and less likely to be covered by private insurance (34%) than those without disabilities (20% Medi-Cal, 14% Medicare, 64% private insurance). See [Appendix A](#) on page 6 for a demographic breakdown of the survey respondents with disabilities.

Black Californians with disabilities experience high rates of both serious physical health conditions and mental health conditions. Approximately two in three (65%) report serious physical health conditions, compared to one in three (32%) of those without a disability. Nearly half (48%) report mental health conditions, compared to one-fifth (19%) of those without disabilities.

Figure 1. Things to Maintain or Improve Personal Health

Q: Here are things that some people do because they think that these things will help them maintain or improve their health. For each one, please tell me how much effort, if any, you put into doing it.

A Great Deal/Quite a Bit, %



Notes: Sample includes 3,325 Black California residents age 18 and older, 663 of whom report a disability. Differences between groups were significant ($p < .05$) for all parts of this question except "Actively trying to reduce stress" and "Focusing on your mental health."
 Source: *Listening to Black Californians*, statewide survey conducted by EVITARUS (March 5–May 8, 2022).

Black Californians with Disabilities Routinely Experience Negative Treatment from the Health Care System

"Even though these findings are stark, they are not necessarily surprising."

-Dante Allen, Executive Director, CalABLE

Black Californians with disabilities are significantly more likely than those without disabilities to report negative health care experiences, including symptoms not being taken seriously and a provider not believing them or suggesting they were to blame for a health problem (Figure 2).

Half of Black Californians with disabilities (50%) indicate they have experienced a time when their pain was not treated adequately by a health care provider, compared to 35% of those without disabilities. And nearly one in five Black Californians with disabilities report being "somewhat" or "very" dissatisfied with their main source of care (19%), compared to 12% of Black Californians without disabilities.

Figure 2. Negative Experiences with Health Care Visits

Q: Thinking more generally about your experiences with health care visits, have any of the following ever happened to you?

Those Who Answered "Yes"



Notes: Sample includes 3,325 Black California residents age 18 and older, 663 of whom report a disability. $P < .05$ for differences between groups.
Source: *Listening to Black Californians*, statewide survey conducted by EVITARUS (March 5–May 8, 2022).

Many Factors Contribute to the Negative Health Care Experiences of Black Californians with Disabilities

People with disabilities who are also members of a racial or ethnic minority, the LGBTQ+ community, or both experience poorer health outcomes and face additional discrimination from the health care system.⁴

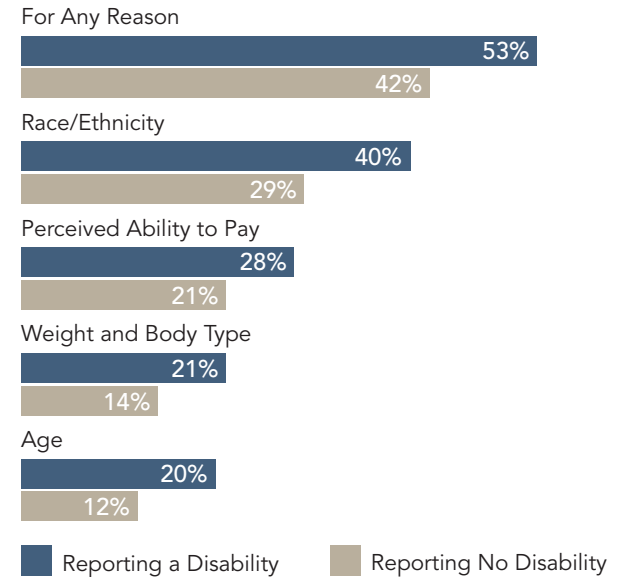
Race and ethnicity, income, insurance coverage, gender identity, and sexual orientation are compounding factors for Black Californians with disabilities in terms of how they experience the health care system. Personal characteristics such as age, weight, or body type also affect how Black Californians with disabilities are treated by the health care system.

More than half of Black Californians with disabilities (53%) report being treated poorly by a doctor or health care provider for any reason. Two in five (40%) of those with disabilities report being treated poorly because of their race or ethnicity. And nearly three in ten (28%) report having been treated poorly because of a perceived inability to pay (Figure 3).

Figure 3. Experience of Poor Treatment Because of Identity

Q: Have you ever been treated poorly by a doctor, dentist, nurse, or other health care provider because of your . . . ?

Those Who Answered "Yes"



Notes: Sample includes 3,325 Black California residents age 18 and older, 663 of whom report a disability. $P < .05$ for differences between groups.
Source: *Listening to Black Californians*, statewide survey conducted by EVITARUS (March 5–May 8, 2022).

Black Californians with Disabilities Often Avoid Care or Adopt Protective Behaviors When Seeking Care

Nearly two in five Black Californians with disabilities (38%) report avoiding care because they felt they would not be treated fairly or with respect, which is significantly more than those without disabilities (23%).

Respondents with disabilities also deploy various strategies to increase their chances of being treated with respect when seeking health care. Over one in three of Black Californians with disabilities (35%) say they minimize questions and concerns to avoid being perceived as “difficult,” compared to one in four of those without disabilities (25%). Half of those with disabilities (51%) report signaling their education and knowledge to providers, compared to 40% of those without disabilities (Figure 4).

Figure 4. Strategies Used to Increase Chances of Being Treated with Respect

Q: Next is a list of things some people may do to increase the chances that they will be treated with respect when seeking health care. For each one, please indicate if you have ever used that approach or strategy when seeking care.

Those Who Answered "Yes"

Signaled to providers that you are educated, knowledgeable, and/or prepared to hold them accountable



Took a companion with you into the exam room during an appointment



Tailored your speech, and/or behavior, to put providers “more at ease,” or to avoid being off-putting



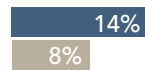
Paid special attention to how you were dressed



Minimized questions and concerns to avoid being perceived as “difficult”



Recorded interactions



■ Reporting a Disability ■ Reporting No Disability

Notes: Sample includes 3,325 Black California residents age 18 and older, 663 of whom report a disability. $P < .05$ for differences between groups.

Source: *Listening to Black Californians*, statewide survey conducted by EVITARUS (March 5–May 8, 2022).

Key Areas for Action

“Disability policy changes should be made at the table before the press conference and include people with disabilities.”

-Eric Harris, Director of Public Policy,
Disability Rights California

Policymakers and health care providers have key roles to play in the improvement of care that Black Californians with disabilities receive. Disability experts recommend the following strategies to address the inequities that Black Californians with disabilities face:

- ▶ **Enforce compliance with the Americans with Disabilities Act (ADA), the Affordable Care Act (ACA), and the Rehabilitation Act of 1973.** Under the ADA, Section 1557 of the ACA, and Section 504 of the Rehabilitation Act of 1973, people with disabilities are entitled to reasonable accommodations to access health care services, including both physical access and communication access. However, too many providers fail to provide sufficient access, often due to the costs associated with accommodating those with disabilities. Ensuring accessibility requires both enforcing existing laws and providing adequate reimbursement or incentives for accommodations.

- ▶ **Include people with disabilities in state data collection efforts.** Although there have been robust state efforts to ensure the collection of data pertaining to race, ethnicity, and language, disability advocates have pointed out that when it comes to improving health care for people with disabilities, there is not enough data. Routinely collecting data on people with disabilities will help researchers compare the health outcomes and health differences of people with and without disabilities, which can in turn lead to better identification of health care and public health solutions.
- ▶ **Train health care providers on holistic care for people with disabilities.** Biases that some providers hold about people with disabilities have real-world repercussions for their health care.⁵ For instance, assumptions that people with disabilities are inherently a high-risk population and less worthy of care have led to forced sterilization, denials of health care, and coercion in treatment.⁶ The disability weightings used in the disability-adjusted life years (DALYs) approach devalues the lives of people with disabilities, which leads to further biases in their care.⁷ Training providers on holistic care for all patients, regardless of their ability, is a first step toward creating a health care system that is less ableist.⁸

- ▶ **Recognize disability as a part of diversity, equity, and inclusion (DEI) efforts.** Many health systems and medical schools have committed to DEI efforts, which often refer to investments in racial or ethnic diversity. Including people with disabilities — who make up 26% of the American population — in DEI efforts would help build a workforce that reflects the needs and experiences of all Californians.⁹

THE TAKEAWAY

Black Californians with disabilities regularly receive health care and engage in health-seeking behaviors. Yet, they often face discrimination or poor treatment when seeking care. Policymakers and health care providers should recognize and address the many challenges that Black Californians with disabilities face when seeking and receiving health care.

Appendix A. Demographics of Respondents Who Reported a Disability (N = 663, Age 18+)

	PARTICIPANTS (#)	PARTICIPANTS (%)		PARTICIPANTS (#)	PARTICIPANTS (%)
GENDER IDENTITY			INSURANCE COVERAGE		
Female	401	55%	Employer-Provided	180	28%
Male	248	45%	Medi-Cal	179	30%
AGE			Medicare	166	32%
18 to 34	56	20%	Other coverage	103	8%
35 to 44	76	12%	Notes: Ns are unweighted. Percentages are weighted. "Prefer not to say" is not shown. Fourteen respondents identified as non-binary or preferred to provide a verbatim response describing their gender. Ten respondents did not share their age. Thirty-five respondents had no health insurance coverage.		
45 to 54	98	14%			
55 to 64	181	26%	Source: <i>Listening to Black Californians</i> , statewide survey conducted by EVITARUS (March 5-May 8, 2022).		
65 to 74	157	18%			
75+	85	10%			
REGION					
Los Angeles County	264	34%			
San Francisco Bay Area	146	21%			
Inland Empire	76	15%			
Other Southern California	64	10%			
North	53	7%			
Central Valley	49	11%			
Central Coast	11	2%			

Endnotes

1. Linda Cummings, [In Their Own Words: Black Californians on Racism and Health Care](#), California Health Care Foundation (CHCF), January 2022.
2. Linda Cummings, [Listening to Black Californians: How the Health Care System Undermines Their Pursuit of Good Health](#), CHCF, October 2022.
3. [“Disability and Health Data System \(DHDS\)”](#), Centers for Disease Control and Prevention (CDC), last updated May 2023.
4. Monika Mitra, et al., [“Advancing Health Equity and Reducing Health Disparities for People with Disabilities in the United States”](#), Health Affairs 41, no. 10 (October, 2022).
5. Omar Sultan Haque and Michael Ashley Stein, [“COVID-19 Clinical Bias, Persons with Disabilities, and Human Rights”](#), Health Hum Rights 22, no. 2 (December, 2020): 285-290.
6. [“Fighting Ableism”](#), Stanford University, accessed October 3, 2023.
7. Trude Arnesen and Erik Nord, [“The value of DALY life: problems with ethics and validity of disability adjusted life years”](#), BMJ (November 27, 1999): 1423-5.
8. Ari Ne’eman, [“I will not apologize for my needs”](#), New York Times, March 23, 2020.
9. Deepa Shivaram, [“Across Federal Workforce, People with Disabilities See Need For More Representation”](#), NPR, July 31, 2021.