POLICY BRIEF

UCLA Center for Health Policy Research

July 2024

The Health of Diverse Californians With Needs for Long-Term Services and Supports

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CHIS california health interview survey

SUMMARY

KEY TAKEAWAYS

- Adults with disabilities who have needs for Long-Term Services and Supports (LTSS) are more likely to experience poor health outcomes than the general adult population in California.
- The psychological health of California adults with disabilities varies by race and ethnicity and by employment status.
- Access to both LTSS and clinical health care is an important driver of health and well-being.

Summary: This policy brief presents data on the health and well-being of home- and community-dwelling adults (18+ years of age and older) with a disability or with long-time chronic conditions who have needs for long-term services and supports (LTSS) and compares their health status with that of the general California population. It further examines how health outcomes vary by race and ethnicity, employment status, unmet needs for LTSS, and access to health care.

The findings can inform the development of policies and programs that improve identification and assessment of need, access to appropriate care, and allocation of resources to better address the ongoing care needs of individuals living with disabilities — in particular, those who are at greatest risk of experiencing poor health and well-being.

Whether an individual is born with a disability or acquires a disability over their lifetime, disability has implications for health, health care access, and quality of life.

BACKGROUND

As the population of California ages, the number of people who are living with disabilities and managing chronic physical, functional, and behavioral health conditions is increasing. Whether an individual is born with a disability or acquires a disability over their lifetime, disability has implications for health, health care access, and quality of life.

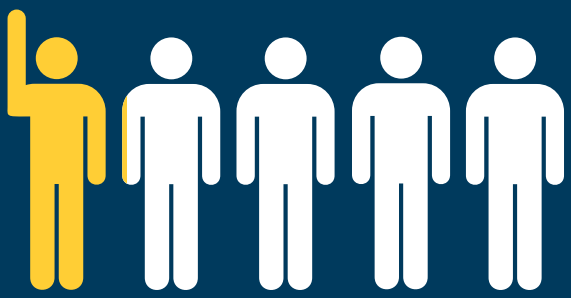
Many individuals living with disability currently use or could benefit from using long-term services and supports (LTSS) to meet their day-to-day needs and optimize their independence, health, and quality of life. LTSS includes a range of physical and social supports that can be provided by a variety of individuals and organizations (e.g., family members and friends, direct care workers, and health and social care professionals) across a broad continuum of care settings (e.g., at home, in the community, or in institutional settings).

Adults who have needs for LTSS = those who are living with disability or managing chronic care needs that have developed over time, and who are using or could benefit from using long-term services and supports (LTSS) to meet their day-to-day needs and optimize their independence, health, and quality of life. Examples of formal/paid services include personal care and homemaker services (e.g., In-Home Supportive Services), nutrition programs (e.g., Meals on Wheels), transportation services (e.g., Access Paratransit), adult day care, and case management services. LTSS also includes informal (and most typically unpaid) care provided by family members, friends, and neighbors. These are the unpaid sources of support upon which many community-dwelling older adults and adults with disabilities rely.

Awareness of and the opportunity to access these supports may influence one's health and well-being.

Previous studies have looked at the unmet needs for LTSS among adults living with chronic physical and behavioral health conditions, functional impairments, and disability, but few have examined the relationship between unmet needs for LTSS and health outcomes such as self-reported health and psychological distress. Existing studies have used national-level data or data in states other than California to examine the relationship between unmet needs for LTSS and health care utilization and community living outcomes;[1, 2] explore how perceptions of neighborhood safety affect the psychological health of older adults;[3] and investigate racial and ethnic differences in measures of self-rated health and sense of control among older adults.[4]

By analyzing self-reported health and psychological distress, this policy brief explores the relationship between unmet needs for LTSS, access to health care, and health and well-being outcomes among adults of all ages in California who have LTSS needs. We used representative population-level data collected from the 2019–2020 California Long-Term Services and Supports (CA-LTSS) Study, a follow-on survey of the 2019–2020 California Health Interview Survey (CHIS).[5] The CA-LTSS Study asked questions about needs, use of services and supports, consequences of unmet needs, and financial concerns of this population.



1 in 5 (21%)

adults with needs for LTSS experienced serious psychological distress in the past month, compared with only **6%** of the general population of California adults.

SURVEY RESULTS

Adults with disabilities who have needs for LTSS are three times more likely to report fair or poor health and to experience serious psychological distress than the general adult population in California.

While we note that the two groups differ with respect to disability status and age, nearly half (46%) of adults with LTSS needs reported fair or poor health, compared with 15% of the general California adult population. One in five (21%) adults with needs for LTSS experienced serious psychological distress in the past month, compared with only 6% of the general population of California adults (data not shown).

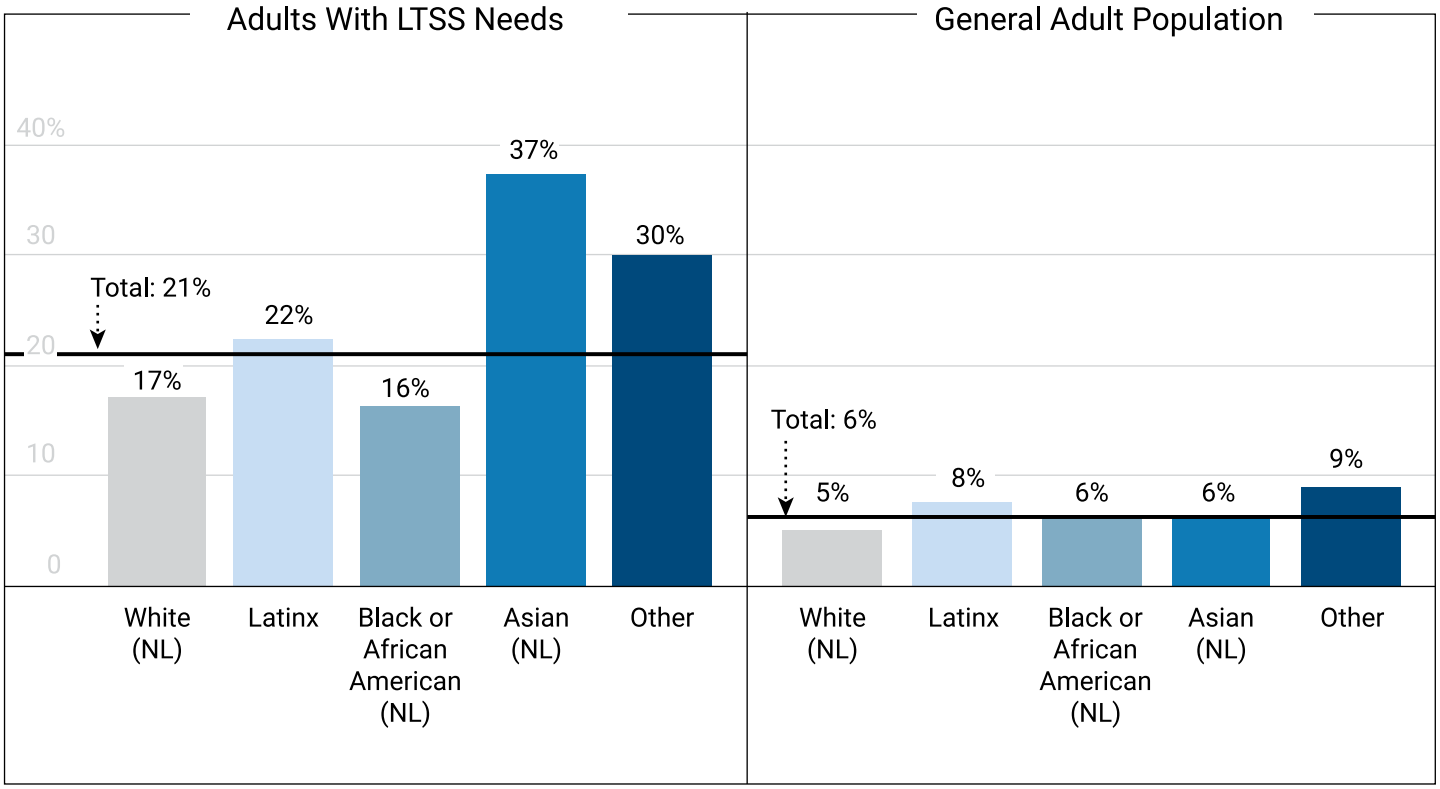
The psychological well-being of adults with needs for LTSS varies by race and ethnicity.

Specifically, larger proportions of Asian adults (37%), adults identifying as Other (30%), and Latinx (22%) adults reported serious psychological distress compared with white (17%) and Black or African American (16%) adults (Exhibit 1).

Interestingly, the patterns of variation in serious psychological distress by race and ethnicity were different in the general adult population. For example, those who identified as Other (9%) or as Latinx (8%) had the highest rates within the general adult population (Exhibit 1), while the general adult population reported much lower rates overall (6%) than the LTSS population (21%). We found no significant differences in self-reported health by race and ethnicity among adults with LTSS needs (data not shown).

The identification of racial and ethnic differences in reported rates of serious psychological distress may reflect gaps in the availability of services, programs, and/or providers who are culturally sensitive and linguistically responsive to the needs and preferences of specific communities.

Exhibit 1 / Percentage of Adults With Needs for LTSS Who Experienced Serious Psychological Distress Compared With the General Adult Population, by Race or Ethnicity, California, 2019–2020



NL = Non-Latinx
Other = American Indian or Alaska Native; Native Hawaiian or Pacific Islander; two or more races
Source: Authors' analyses of 2019–2020 California Long-Term Services and Supports (CA-LTSS) Study and 2019–2020 California Health Interview Survey (CHIS) data

Awareness of these differences is essential to the design and delivery of appropriate outreach strategies and accessible pathways to both preventive care and treatment.

Employment status is a potential driver of health and well-being among adults with LTSS needs.

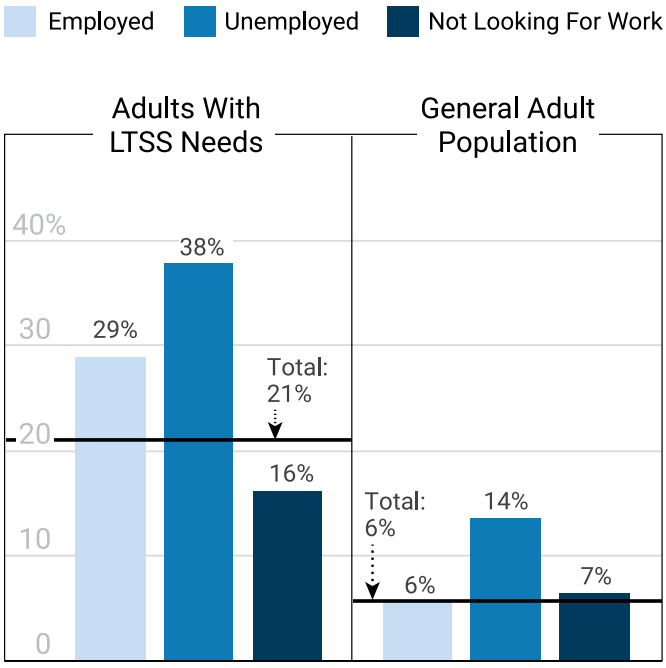
Employment has direct implications for economic security and opportunities to access health care through employer-based health insurance and other benefits. When we examined serious psychological distress, we found significant differences by employment status within the LTSS population, as well as between the LTSS population and the general population of adults in California.

Unemployed adults with LTSS needs (38%) were more than two times as likely as those not looking for work (16%) to experience serious psychological distress. Interestingly, employed adults with LTSS needs also had significantly higher rates of serious psychological distress (29%) than those who were not looking for work (16%) (Exhibit 2).

The patterns we found in the general adult population in California were different. Those who were unemployed (14%) were the most likely to experience serious psychological distress, at nearly twice the rate of both employed adults (6%) and adults not looking for work (7%). While unemployment is associated with the highest rates of serious psychological distress within both population groups, being employed appears to have different implications for adults with LTSS needs (i.e., those who are working while also managing chronic health conditions and/or disabilities) (Exhibit 2).

When we looked at the relationship between health outcomes and employment status, we found in both populations that adults who were not looking for work or who were unemployed were more likely to report fair or poor health than adults who were employed (data not shown).

Exhibit 2 / Percentage of Adults With Needs for LTSS Who Experienced Serious Psychological Distress Compared with the General Adult Population, by Employment Status, California, 2019–2020



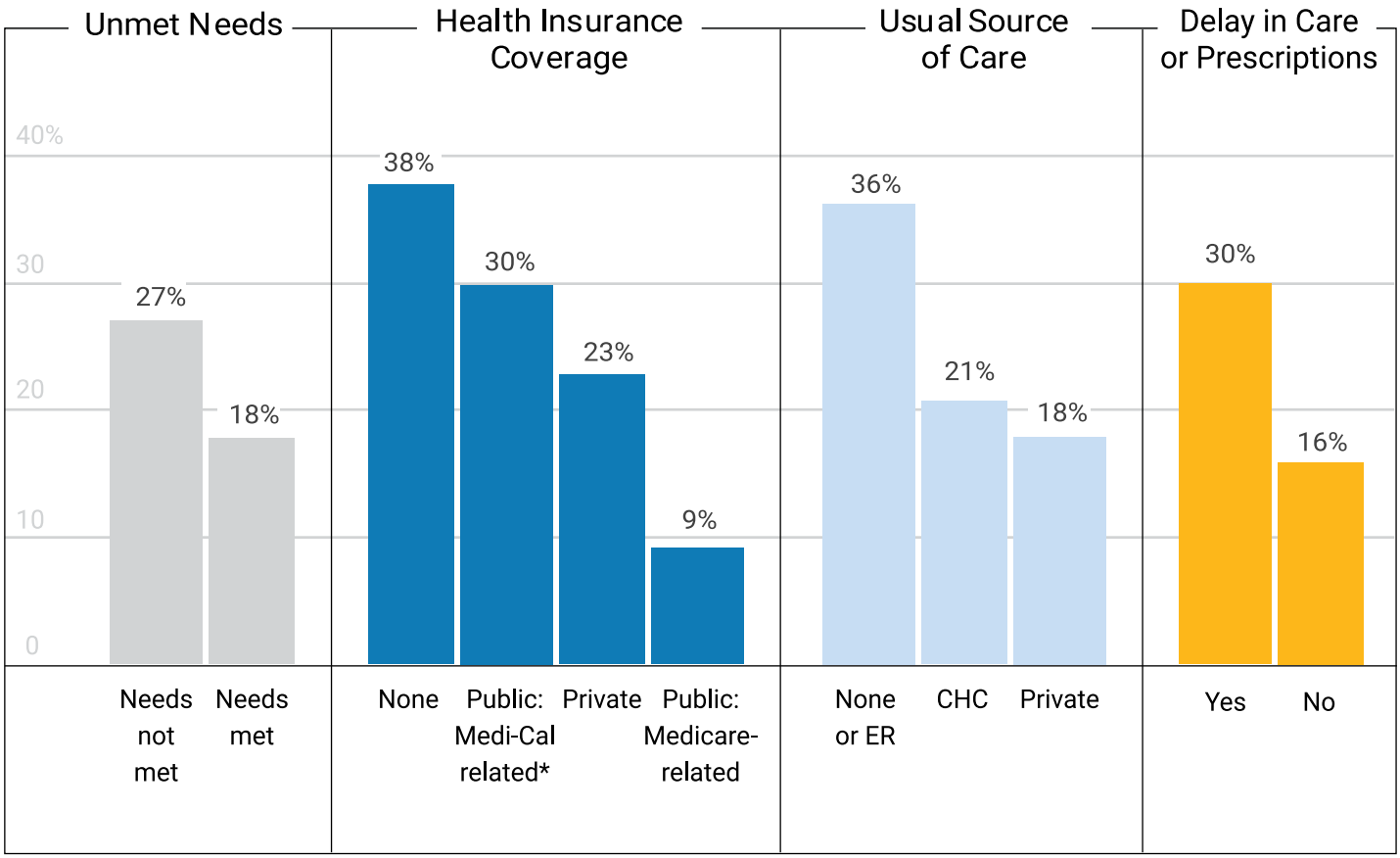
NL = Non-Latinx
Other = American Indian or Alaska Native; Native Hawaiian or Pacific Islander; two or more races
Source: Authors' analyses of 2019–2020 California Long-Term Services and Supports (CA-LTSS) Study and 2019–2020 California Health Interview Survey (CHIS) data

Access to both LTSS and clinical health care is a potential driver of health and well-being.

Looking only at the population of adults and older adults with LTSS needs in California, we examined the association between serious psychological distress and access to both LTSS and clinical health care using measures of unmet needs for LTSS, health insurance coverage, usual source of care, and delays in receiving care or prescriptions.

We found that access to both LTSS and clinical health care is a potential driver of health and well-being among adults with LTSS needs in California (Exhibit 3).

Exhibit 3 / Percentage of Adults With LTSS Needs Who Had Serious Psychological Distress, by Unmet Needs, Insurance Coverage, Usual Source of Care, and Delays in Care or Prescriptions, California, 2019–2020



*"Public: Medi-Cal related" includes dually eligible enrollees (i.e., those who are insured by both Medi-Cal and Medicare)
ER = emergency room; CHC = community health center
Source: Authors' analyses of 2019–2020 California Long-Term Services and Supports (CA-LTSS) Study and 2019–2020 California Health Interview Survey (CHIS) data

Findings:

- A larger proportion of adults who reported unmet needs for LTSS experienced serious psychological distress (27%) compared to those who did not report unmet needs (18%).
- Adults with LTSS needs who had no health insurance (38%) or who had Medi-Cal–related public insurance (30%) were more likely to report serious psychological distress compared to those with private insurance (23%) or Medicare-related public insurance (9%).
- More than one-third of the adults who had no usual source of care (36%) experienced serious psychological distress, which is higher than the proportions among those who used a community health center (21%) or a private usual source of care (18%).
- Close to one-third of the adults who reported delays in receiving care or prescriptions (30%) experienced serious psychological distress, almost two times the figure for those who did not experience such delays (16%).

For additional survey results related to the economic and social drivers of health and well-being for California older adults and adults with LTSS needs, please see the two fact sheets released in tandem with this policy brief, *Financial Worries of Diverse Californians With Needs for Long-Term Services and Supports* and *How a Sense of Neighborhood Cohesion Affects the Health of Diverse Californians With Needs for Long-Term Services and Supports*.

Close to

1 in 3 (30%)

adults with LTSS needs who reported delays in receiving care or prescriptions experienced serious psychological distress.

POLICY IMPLICATIONS AND RECOMMENDATIONS

Aging and disability occur across a person's lifetime, and individual needs for LTSS may develop at any time. Understanding and responding to the comprehensive, or holistic, needs of a diverse population of older adults and adults with disabilities in California requires careful attention to data that can highlight population-level health needs and disparities and identify potential gaps in access to appropriate LTSS and clinical health care.

The data presented in this policy brief show that adults with LTSS needs have higher rates of poor self-reported health and serious psychological distress than the general population of adults in California. Furthermore, the experience of serious psychological distress varies by racial and ethnic group and employment status, and those who have unmet needs for LTSS and also experience barriers to accessing health care services are at even greater risk of poor mental health outcomes.

> Those who have unmet needs for LTSS and also experience barriers to accessing health care services are at even greater risk of poor mental health outcomes.

Advancing existing and promising initiatives with the potential to meet these needs could reduce these adverse outcomes. We recommend improving access to LTSS for eligible populations through educating the public on existing program availability, minimizing administrative burden on the consumer, improving care coordination, and better connecting LTSS recipients to behavioral health care.

Current initiatives such as the Aging and Disability Resource Connection (ADRC) program aim to ensure that the public knows what services and supports are available for culturally and linguistically diverse older adults and adults living with disabilities. ADRC uses a "No Wrong Door" (NWD) system to coordinate and facilitate access to a broad range of culturally and linguistically appropriate services.[6]

This program and other related efforts need to be expanded to reach more people and places, and they also need to be enhanced to reduce existing administrative burdens and provide more effective referrals and seamless navigation support. Building a universal process for assessment and a coordinated system of referrals across relevant agencies and departments could help improve access to services that have historically been delivered separately, in silos.[7]

Our findings further suggest the need to ensure access to health insurance coverage that is adequate and connects with a usual source of care that is timely, responsive, and of good quality. For individuals who are eligible for Medi-Cal, a series of transformation initiatives known as CalAIM recognizes that a more person-centered, holistic, and well-integrated delivery system is essential for bridging existing silos that constrain the effective provision of comprehensive care.[8] If realized as intended, CalAIM holds great promise to better address both acute and long-term health and social care needs through services provided in traditional medical and institutional settings as well as at home and in the community.

CalAIM's Enhanced Care Management (ECM) program is especially pertinent for people with LTSS needs, who often have to navigate complex and fragmented systems to get the care they need.[9] As CalAIM's behavioral health initiative evolves, more attention must be paid to behavioral health needs and outcomes that may be further compounded by aging and/or living with disability.[10]

Proactive assessments could be extended to those facing additional barriers to accessing care. For example, through CalAIM's justice-involved initiative, targeted outreach to those with disabilities who will be leaving incarceration would help to ensure that these individuals are assessed and that they apply for LTSS prior to reentry into the community.[11] Community Supports, another CalAIM program, can be paired with ECM services to further address social drivers of health and meet a number of LTSS population needs, such as housing, food, and transportation.[12]

Finally, our findings related to employment status indicate a potential need for pathways to meaningful employment for adults with chronic care needs or disability, along with assurances that those who are employed or who seek employment are appropriately supported and compensated. Increased opportunities for employment in workplaces that provide necessary accommodations for people with disabilities can help level the playing field by addressing differential rates of pay or opportunity and reducing stressors associated with both physical and interpersonal barriers.

Physical barriers include transportation, design, and accessibility, while interpersonal barriers involve discrimination, stigma, and harassment. Barriers of both kinds can impede comfort, productivity, and equitable pay for individuals with LTSS needs. The California Department of Rehabilitation offers career counseling and information and referral services to help connect those with disabilities with opportunities for community employment.[13]

Increased opportunities for employment in workplaces that provide necessary accommodations for people with disabilities can help level the playing field by addressing differential rates of pay or opportunity and reducing stressors associated with both physical and interpersonal barriers.

Employment issues may be different for older adults who have LTSS needs. An increasing number of older adults are working well into what has traditionally been considered their "retirement" years. While this trend may reflect either personal preference or economic necessity, low-income older adults with LTSS needs may be disincentivized from working for fear of losing their Medi-Cal coverage. Increasing the income limit for the Medi-Cal Working Disabled Program (WDP), now 250% FPL, would allow individuals to work and continue receiving Medi-Cal coverage and access to LTSS.[14] Increasing the unearned income limit (currently at the SSI rate) can also remove barriers that force individuals to choose between employment and health care. At present, uptake of the WDP is quite low. Improving awareness and removing administrative barriers to enrollment can also help.[7]

Methodology

A total of 3,990 adults (9%) who responded to the 2019 and 2020 California Health Interview Surveys (CHIS) answered "Yes" to at least one of the following three questions and were therefore eligible to participate in the California Long-Term Services and Supports (CA-LTSS) Study:

1) Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?

2) Do you have difficulty dressing or bathing?

3) Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone, such as visiting a doctor's office or shopping?

Among the 2,030 respondents who completed the CA-LTSS survey, 54.4% reported serious difficulty concentrating, remembering, or making decisions; 35.8% reported difficulty with personal care; and 52.7% reported difficulty with routine care. All results are weighted based on population characteristics in California.

Self-rated health was assessed based on participants' description of their health as excellent, very good, good, fair, or poor. We categorized "good," "very good," and "excellent" as being in good health, and "poor" and "fair" as not being in good health.

Serious psychological distress was assessed using the Kessler 6 (K6) scale. The questionnaire asked participants how they had been feeling during the past 30 days with respect to the following six items: 1) nervous; 2) hopeless; 3) restless or fidgety; 4) so depressed that nothing could cheer you up; 5) everything was an effort; 6) worthless. Each item was coded as: 0 = None of the time/ Never; 1 = A little of the time; 2 = Some of the time; 3 = Most of the time; 4 = All of the time. The resulting range for psychological distress is 0–24. A score of 13 or greater indicates serious psychological distress.

Funder Information

This policy brief and related fact sheets were supported by the California Health Care Foundation (CHCF), which works to improve the health care system so that all Californians have the care they need. Visit www.chcf.org to learn more.

The primary data source for this policy brief, the California Long-Term Services and Supports (CA-LTSS) Survey, was funded by the California Department of Health Care Services (Grant Agreement 18–95340).

Acknowledgments

The authors are deeply grateful for the thoughtful and insightful reviews of this policy brief provided by Sabrina Epstein of Disability Rights California, Hagar Dickman of Justice in Aging, Viviana Criado of the Los Angeles Alliance for Community Health and Aging, and Susan Babey of the UCLA Center for Health Policy Research.

Suggested Citation

Kietzman KG, Chen L, Juturu P. 2024. *The Health of Diverse Californians With Needs for Long-Term Services and Supports*. Los Angeles, CA: UCLA Center for Health Policy Research.

The California Health Interview Survey covers a wide array of health-related topics, including health insurance coverage, health status and behaviors, and access to health care. It is based on interviews conducted continuously throughout the year with respondents from more than 20,000 California households. CHIS interviews were offered in English, Spanish, Chinese (both Mandarin and Cantonese), Vietnamese, Korean, and Tagalog. CHIS is designed with complex survey methods requiring analysts to use complex survey weights in order to provide accurate variance estimates and statistical testing. CHIS is a collaboration of the UCLA Center for Health Policy Research, the California Department of Public Health, the California Department of Health Care Services, and the Public Health Institute. For other information about CHIS, visit chis.ucla.edu.

Endnotes

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9 CalAIM Enhanced Care Management program: https://calaim.dhcs.ca.gov/pages/enhanced-care-management

10 CalAIM Behavioral Health Initiative: https://www.dhcs.ca.gov/Pages/BH-CalAIM-Webpage.aspx

11 Justice in Aging: https://justiceinaging.org

12 CalAIM Community Supports program: https://calaim.dhcs.ca.gov/pages/community-supports

13 Career Counseling and Information and Referral Services, California Department of Rehabilitation: https://dor.ca.gov/Home/CCIR

14 Medi-Cal Working Disabled Program (WDP), California Department of Health Care Services: https://www.dhcs.ca.gov/services/Pages/TPLRD_WD_cont.aspx

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ISSN 2691-7475

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PB2024-6

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