About 14 million adults in the United States need home- and community-based services (HCBS) in order to maintain their independence and support their quality of life. The demand for HCBS is expected to increase dramatically in the coming years as the baby boomer generation (those born between 1946 and 1964) ages, and as advances in medicine and technology help people who have multiple chronic conditions and/or disability live longer.

Unmet need for HCBS has been associated with poor health and social outcomes among older adults and adults with physical disabilities who use Medicaid benefits, as well as with high levels of adverse consequences among older adult Medicare beneficiaries. The ability to access long-term services and supports (LTSS) at home—both paid and unpaid—is essential to maintaining the physical and mental health and well-being of older adults and adults with disabilities. LTSS based in the home and the community aim to facilitate independent living and can be instrumental in preventing or delaying unnecessary or premature institutionalization.

Exhibit 1: Percentage of Older Adults and Adults With Disabilities Experiencing Unmet Need for Help at Home, California, 2019–20

<table>
<thead>
<tr>
<th>Do or do not need help for:</th>
<th>Routine Care</th>
<th>Personal Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do not need help</td>
<td>45.4%</td>
<td>79.2%</td>
</tr>
<tr>
<td>Need help</td>
<td>54.6%</td>
<td>20.9%</td>
</tr>
</tbody>
</table>

Of those who need help:
- Get no help: 36.4% / 4.5%
- Could use more help: 60.2% / 60.5%
- Get all needed help: 3.4% / 4.5%

Source: Authors’ analyses of 2019-20 California Long-Term Services and Supports (CA-LTSS) Survey, a follow-on survey of the California Health Interview Survey (CHIS)
In this fact sheet, we provide a state-level population view of the needs of older adults (ages 65 and older) and adults with disabilities in California. Data were gathered from the California Long-Term Services and Supports (CA-LTSS) study, a follow-on survey of the 2019 and 2020 California Health Interview Surveys (CHIS). We examine the prevalence of need and unmet need for LTSS and document the adverse consequences of unmet need among adults in California using different measures of cognitive and functional disability (i.e., difficulty concentrating, remembering, and making decisions; difficulty with routine care needs, such as doing chores or errands; and difficulty with personal care needs, such as eating, dressing, bathing, or getting around inside the home).

More than half (54.6%) of those who completed the LTSS survey reported needing help from another person for routine care, while about 1 in 5 (20.9%) reported needing help with personal care. For both groups, nearly 2 in 5 respondents reported either that they could use more help or that they get no help at all (Exhibit 1).

Survey results also highlight racial/ethnic differences in level and type of need. Black/African American and biracial/multiracial respondents were among those most likely to report needing help with routine care (73.5% and 72.4%, respectively) and with personal care (39.4% and 22.5%) (Exhibit 2). In contrast, American Indian and Alaska Native (AIAN) and Asian respondents were...
significantly less likely to report needing help with personal care (12.4% and 9.5%, respectively) (Exhibit 2).

These data also illuminate adverse consequences experienced by adults with unmet needs for LTSS. Nearly half (45.8%) reported staying at home due to difficulty going outside, 18.8% reported going without groceries or personal items due to difficulties shopping, and more than 1 in 4 (27.4%) reported making a mistake when taking their medications due to difficulty keeping track of them (Exhibit 3). The exhibit also shows the extent to which adults with specific types of cognitive or functional disabilities were likely to experience these adverse consequences compared to the overall population of older adults and adults with disabilities in California.

**Implications**

People with disabilities experience greater health disparities than those without disabilities. Yet because this population has been underrepresented in studies, our ability to identify gaps in care and to better understand why they have poorer health outcomes is limited. When we consider the unmet needs of both older adults and people with disabilities, we need to apply a health equity lens and direct supports to those who are among the most vulnerable and likely to have unmet needs for assistance.
California’s Master Plan for Aging (MPA) is documenting and tracking the needs of older adults and adults of all ages who are living with disability. The goals and strategies advanced through the MPA can support both statewide and local efforts to better respond to unmet needs. One important step is to increase consumer knowledge of and access to available supports and services in the community. Special efforts should be made to reach those with the greatest amount of unmet need and those who are experiencing adverse consequences, particularly when disparities between needs and services are identified by specific sociodemographic characteristics. Efforts to increase the quality and size of the paid caregiver workforce are also essential if California is to meet the ever-increasing demand for HCBS. Finally, better support is urgently needed for family and friend caregivers, who provide most of the help needed to keep older adults and adults with disabilities safe and healthy at home, where the vast majority prefer to be.

Methodology

A total of 3,990 adult respondents to the 2019 and 2020 CHIS (9%) answered yes to at least one of the following three questions and were therefore eligible to participate in the CA-LTSS survey:

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.

Funder Information

This fact sheet was funded by the California Department of Health Care Services (Grant Agreement 18-95340). The content is solely the responsibility of the authors and does not necessarily represent the official views of the California Department of Health Care Services.

Suggested Citation


Endnotes


7 California Master Plan for Aging: https://mpa.aging.ca.gov/