

Reducing Costs for Families and States by Increasing Access to Home- and Community-Based Services

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Introduction

The majority of individuals who need long-term services and supports (LTSS) in the US rely on unpaid assistance from family and friends. Among the approximately 11 million individuals with LTSS needs living in the community, 92% receive unpaid assistance and only 13% receive any form of paid assistance.¹ Nationally, there are over 53 million family caregivers.² The economic value of the unpaid care they provide is estimated to be over \$470 billion annually.³

Unmet needs and long waiting lists for Medicaid Home and Community Based Services (HCBS) place significant strain and economic burden on individuals with disabilities and their families. Even among individuals receiving Medicaid HCBS there are high levels of unmet needs for services.⁴ When individuals do not have needed HCBS, their health and community living outcomes are worse. Moreover, the health and economic well-being of family caregivers erodes, often resulting in undesirable placements in more costly nursing home and institutional settings.

Increasing Access to HCBS Can Reduce Out-of-Pocket Costs for Families

Over three-quarters of family caregivers (78%) report out-of-pocket expenses related to caregiving, including household, medical, personal care, and other expenses.⁵

- ▶ Average annual out-of-pocket costs for caregivers is \$7,242, approximately one quarter (26%) of their income.
- ▶ Black and Hispanic/Latinx families report greater financial strain, with annual out-of-pocket expenses totaling 34% and 47% of their income, respectively.

A recent poll conducted by The Kaiser Family Foundation found that about one in five adults say *they* or *their family member* need new or additional support from paid nurses or aides beyond what they are currently getting. The most common reason why people haven't gotten the support they need is cost.⁶

Increasing Access to HCBS Can Strengthen Employment and Financial Well-Being of Family Caregivers

Six in 10 family caregivers report having experienced at least one impact or change to their employment situation as a result of caregiving including:⁷

- ▶ Going in late, leaving early, or taking time off (53%)
- ▶ Going from full-time to part-time/reducing hours (15%)
- ▶ Taking leave of absence (14%)
- ▶ Turning down a promotion (7%)
- ▶ Giving up work entirely (6%)
- ▶ Retiring early (5%)

Approximately half of family caregivers report at least one financial impact as a result of caregiving including:⁸

- ▶ Stopped saving (28%)
- ▶ Took on more debt (23%)
- ▶ Used up personal short-term savings (22%)
- ▶ Left bills unpaid/paid them late (19%)
- ▶ Borrowed money from family or friends (15%)

Enhancing Wages for Home Care Workers Assists Low-Income Families and Can Reduce Gaps in Services and Supports

- ▶ The median annual income for home care workers is \$18,100.⁹
 - ▶ One in six home care workers (16%) lives in a household below the federal poverty line and 45% live in low-income household (less than 200% of the federal poverty line).

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- ▶ Inability to find and maintain workers and high turnover rates result in individuals going without needed care and additional stress on unpaid family members who fill gaps. The COVID-19 pandemic has exacerbated long-standing issues low wages, shortages of the direct care workers, and unmet needs for individuals and families.¹⁰

Shifting from Nursing Homes and Other Institutions to HCBS Can Produce Cost Savings for States

- ▶ Increases in HCBS, coupled with rebalancing efforts, allow states to better contain overall LTSS spending. One study found that gradual rebalancing, by roughly two percentage points annually, can reduce spending by about 15 percent over ten years.¹¹
- ▶ States with robust Money Follows the Person Programs, which assist individuals in transitioning from nursing homes and institutions back to the community, have reduced nursing home occupancy rates and utilization of institutional LTSS, which on average cost more.¹²

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