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Incorporating Long-Term Services and Supports in Health Care Proposals: Cost and Distributional Considerations

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Executive Summary

Recent health care reform proposals have included coverage for long-term services and supports (LTSS), reflecting a fundamental change in the way many policymakers discuss health care. To inform broader discussions of these health care reform proposals, we project costs and distributional effects for three stylized proposals for public LTSS benefits. Each proposal would significantly expand the public role in financing LTSS relative to current law. All proposals would have broad eligibility criteria and generous benefit packages, consistent with recent proposals for single-payer health care plans, and would address family burdens and care inadequacies under current law. Our stylized scenarios are intended to represent some proposals' intentions without exactly matching any specific proposal. The three public LTSS benefit options are as follows:

- **Option 1 (Base): Expanded access to home- and community-based services based on Health Insurance Portability and Accountability Act standards.** This option would use Health Insurance Portability and Accountability Act definitions of disability for eligibility and provide a broad package of home- and community-based services. It would increase total LTSS spending by nearly \$240 billion and federal spending by \$355 billion. It would also greatly expand formal service use, reduce state Medicaid responsibilities, and alleviate family cost-sharing burdens.
- **Option 2: Expanded access to home- and community-based services with an institutional benefit.** This second option would build on the first reform option, using the same definition of disability and providing the same home- and community-based services, but would also include institutional care benefits. This option would increase total LTSS spending by about \$255 billion and federal spending by \$450 billion; this difference in cost from option 1 largely owes to further reduced state burdens.
- **Option 3: Expanded access to home- and community-based services based on less strict standards.** This option would use a broader disability definition and thus cover significantly more people. We project that it could increase total spending by \$321 billion and federal costs by almost \$526 billion.

Families across the income distribution would benefit from expanded LTSS under all three options; people with the lowest incomes would receive the greatest benefits, and those in the middle of the income distribution would experience relief from cost sharing given their greater exposure to high out-of-pocket LTSS costs. All families would thus receive protection from a risk for which few are now covered.

Given the lack of precedent for these proposals, we present ranges for our projections to underscore their uncertainty and dependence on assumptions.

Incorporating Long-Term Services and Supports in Health Care Proposals

Introduction

Recent health care reform proposals, including some from candidates seeking the Democratic Party nomination for president, have included coverage for long-term services and supports (LTSS), reflecting a fundamental change in the way many policymakers discuss health care. These proposals bolster the case for more closely examining LTSS financing and service delivery in the United States.

By many accounts, the risk of needing years of supportive care is one of the greatest uninsured financial risks Americans face (Johnson and Favreault 2020), and many are unaware of this risk (Associated Press-NORC 2016, 2017). Although often considered a late-life issue, illness or injury can result in the need for LTSS at any age. Yet, in the United States, there are no universal LTSS benefits,¹ so preparing for LTSS needs is largely an individual responsibility. The current system combines a small—and shrinking—private insurance market with means-tested coverage for the indigent through Medicaid (O’Keeffe et al. 2010),² and many states have waiting lists for Medicaid-funded home- and community-based services (HCBS; Musumeci, Chidambaram, O’Malley Watts 2019a). This leaves most Americans effectively uninsured, or at best underinsured, for LTSS risk, and costs for LTSS can be daunting. In 2019, the median cost for a year of home care was over \$50,000, and the cost for a year in a semiprivate room in a nursing home was over \$90,000 (Genworth 2019)—beyond many families’ reach. Because of this gap between needs, family finances, private insurance, and public support, many people rely heavily on unpaid family care, are burdened by large out-of-pocket costs for formal care, or fail to receive needed care.

These financing challenges are exacerbated by disparities in disability. Most people will experience frailty and decline in function as they age (Johnson 2019). However, these challenges come earlier and last longer for those with less education, lifetime earnings, and wealth. Those disabled early in life are often the most economically vulnerable, because the ability to save and prepare for needs may be at best limited.

Recent efforts to revamp this patchwork LTSS financing system have either failed or stalled.³ Considering these new proposals for LTSS benefits is thus an important next step for the policy community, dovetailing with other recent efforts to jumpstart conversations on LTSS financing reform (Bipartisan Policy Center 2014; Commission on Long-Term Care 2013; LeadingAge Pathways 2013; Long-Term Care Financing Collaborative 2016; O’Leary 2014; Veghte et al. 2019).

The Congressional Budget Office (CBO) has outlined some design issues to consider when developing and evaluating single-payer health care proposals (CBO 2019):⁴ enrollment and eligibility, covered services, cost sharing, the role of current systems (including private health insurance), provider roles and rules, payment rates, cost containment and financing, and administration. CBO has also identified several considerations for LTSS benefits within a single-payer plan, one of which is the possibility that strapped families who provide large amounts of unpaid care would supplement—and in some cases replace—family care with paid care. Further, people who are eligible for benefits but do not participate under current law may become more aware of coverage and take up benefits. CBO analysts further noted that families considering participating will likely be sensitive to cost sharing. However, CBO has not yet released cost or distributional estimates for new LTSS benefits under these types of plans. There is thus an urgent need for objective, unbiased information about the potential costs and distributional effects of expanded LTSS benefits in a revamped health care system.

We try to fill this void by presenting estimates of the 2020 and 10-year costs and distributional effects of three stylized proposals that would greatly expand LTSS access, consistent with the objectives of some prominent single-payer plans. However, our three stylized scenarios do not match exactly any specific proposal. All three scenarios are quite generous relative to current law. They provide universal coverage for LTSS for those eligible to participate in a single-payer plan regardless of their income and assets and whether they purchased a long-term care insurance policy. The scenarios vary in the benefits provided and the strictness of the eligibility criteria enrollees must meet to establish their disability and receive services. Changes to LTSS programs’ disability criteria can significantly change the population defined as qualified to receive services. (We do not provide estimates for the distributional effects of policy changes that would finance these stylized options given that these proposals do not address how to finance the LTSS components of large changes to the health care system.)

The Three Stylized Options

Option 1, or expanded HCBS access based on Health Insurance Portability and Accountability Act (HIPAA) standards, provides universal HCBS benefits and relies on HIPAA disability criteria and benefit limitations that roughly characterize current Medicaid and private LTSS insurance. This option's primary difference from current law is that it does not factor income, assets, or purchase of private long-term care insurance into benefit eligibility. This first stylized proposal is anchored to a proposal that has been actuarially analyzed in recent years, enhancing the transparency of our key assumptions and allowing us to compare our projections against an independent source.

Option 2, expanded HCBS with an institutional benefit, adds limited institutional care to the first option, again restricting eligibility to those meeting the relatively high disability threshold in current programs.

Option 3, expanded access based on less strict standards, is more expansive and designed to be more consistent with the most generous proposed single-payer legislation under debate. It would extend LTSS access to more people, including those whose disabilities are below the thresholds more commonly used by public LTSS programs and private insurance companies. Under this option, people meeting the disability criteria could receive HCBS or institutional care. Because of the expanded eligible population, estimates for this option are the most speculative, but we ground them, to the extent possible, in estimates of current LTSS utilization.

We present sensitivity analyses to highlight the uncertainty of projections under all three options, especially the third. Because data on LTSS needs and use are quite limited and these proposals are unprecedented in their scope, we cannot estimate the likely effects with confidence. Instead, we provide some broad contours grounded in a plausible range of alternative assumptions.

We juxtapose these projections with estimates of current-law spending, describing how total costs might increase and shift across payers. And we describe who will likely receive new paid services under the plan. We conclude that overall spending on LTSS could increase by nearly three-quarters under our base plan (option 1) and would likely more than double under the more generous program (option 3). Families across the income distribution would benefit from expanded LTSS under all three options; people with the lowest incomes would receive the greatest benefits, and those in the middle of the income distribution would experience relief from cost sharing, given their greater exposure to high out-of-pocket LTSS costs under current policy. All families would thus receive protection from a risk for which few are now covered. Many service costs state governments currently partially fund would transfer to the federal government.

Background: What Is LTSS? Who Receives it? Who Provides it? Who Pays for It under Current Law?

Before delving into how many people new LTSS programs might reach and how much they might change costs for health care plans, we first provide some background. We define terms, describe prevalence of LTSS needs and use, and identify the LTSS beneficiaries, providers, and payers under current law to give context for some of the choices and assumptions we make in our analyses of the proposed new programs. Other sources provide more detailed information (Kaye, Harrington, and LaPlante 2010).

What Is LTSS?

Long-term care is typically defined as a range of services and support for personal care needs when an individual cannot perform them independently because of disability. Most LTSS are not skilled medical care, but rather help with basic personal tasks of everyday life,⁵ sometimes called activities of daily living (ADLs). ADLs include eating, bathing, dressing, toileting, and transferring (e.g., getting out of bed or into a chair). Instrumental activities of daily living (IADLs) are more complex tasks that typically require a higher-level of functional capacity, such as preparing meals, shopping, doing housework, managing medications, and using the telephone. IADL limitations may be less debilitating than ADL disabilities because one may not need to perform IADLs every day, but IADLs are important for independent living, and limitations often arise as one's cognitive abilities decline.

LTSS needs arise when a person does not have the cognitive or physical ability to perform ADLs or IADLs without assistance from another person for an extended period.⁶ One common threshold for defining LTSS needs that specifies both severity and duration of need is found in HIPAA regulations about the eligibility standards private long-term care insurance plans must meet for purchasers to qualify for tax subsidies.⁷ We refer to those standards as the HIPAA thresholds. They are defined as (1) a need for substantial assistance with at least two ADLs that a person cannot perform for at least 90 days,⁸ or similar level of disability, or (2) a need for substantial supervision for health and safety threats due to severe cognitive impairment.

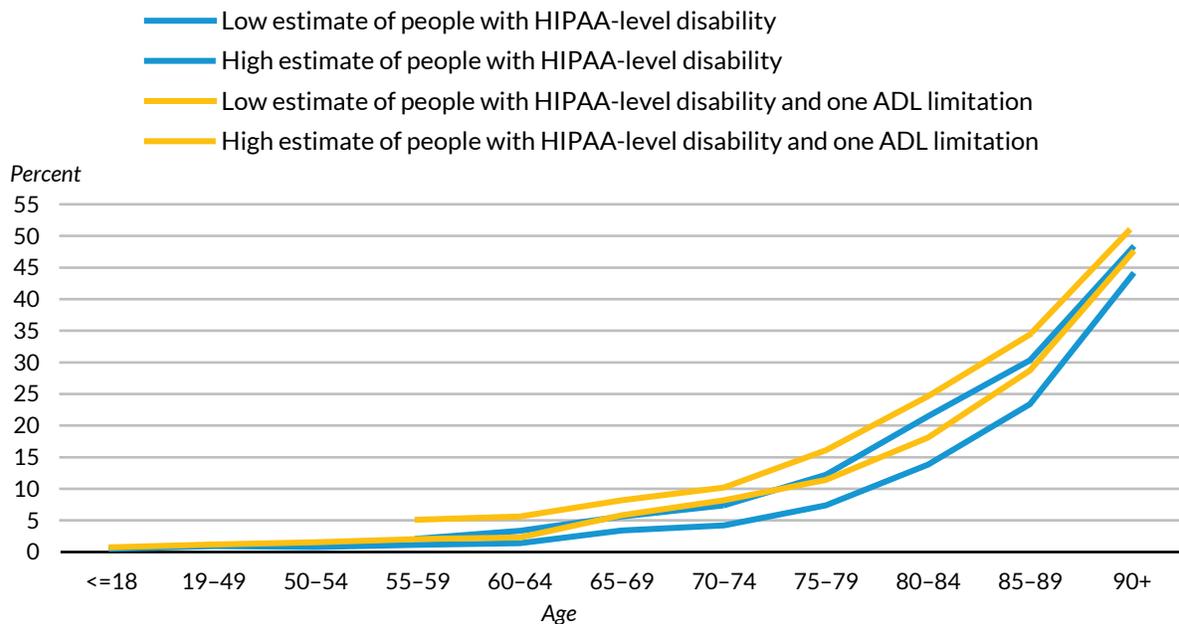
How Many People Need LTSS?

Hado and Komisar (2019) estimate that about 14 million US adults needed LTSS in 2018: 12.6 million in the community and 1.4 million in institutions. Estimates for children vary widely depending on the disability level one uses. More comprehensive information is available on older adults' needs (Freedman

and Spillman 2014). Disability estimates are generally sensitive to survey sample frameworks and question wording (Freedman et al. 2013).

LTSS needs are closely related to age, and the share of people needing these services grows rapidly at older ages (figure 1). Estimates vary across datasets, so figure 1 plots estimates from four datasets, showing the high and low estimates in each age range when we have at least two data sources. Our estimates of the share of adults whose disabilities meet the HIPAA standard rises from 2 percent at ages 55 to 59 to about 44 to 47 percent at ages 90 and older. To project potential eligibility under an LTSS program with expansive eligibility criteria, we also expand the disability standards to include those who report one ADL limitation. Including this population increases disability prevalence by about 2 to 4 percentage points at most ages, leading to a total increase of about one-quarter to one-half, depending on the age range.

FIGURE 1
Higher- and Lower-Bound Estimates of Disability Prevalence, by Age
and Presence of HIPAA-Level Disability or Expanded Disability, Including One ADL Limitation



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Sources: Tabulations by Brenda Spillman from the 2015 National Health and Aging Trends Study and Melissa Favreault from the Health and Retirement Study, Medicare Current Beneficiary Survey, and National Health Interview Survey.

Notes: HIPAA = Health Insurance Portability and Accountability Act. ADL = activity of daily living. Indicators and populations differ across the survey datasets used. The analyses based on the Health and Retirement Study use scores from the Telephone Interview for Cognitive Status plus evaluations from proxy respondents and exit interviews. The Medicare Current Beneficiary Survey analyses use self-reports of Alzheimer’s plus diagnosis codes in payment records. These codes include 290.x, 294.x, and 331.x (ICD9) and F01050, F01051, F0390, F0391, G300, G301, and G3183 (ICD10) and cover a range of dementia types (Alzheimer’s disease, vascular, Lewy body, and unspecified). The National Health and Aging Trends Study assigns

probable cognitive impairment based on reported diagnosis of dementia or Alzheimer's or proxy report of two or more behavior changes on the AD8 screener, plus respondents' performance on questions regarding various aspects of cognition. The National Health Interview Survey does not include people living in institutions, so the estimates for ages younger than 55 understate disability prevalence.

Many researchers have also found that age-specific LTSS needs differ by social status, with people with less education or lower lifetime earnings more likely to become disabled and need LTSS (Favreault, and Dey 2016, Johnson 2019). Income differences in disability are present for children as well as adults (Singh and Lin 2013).

Importantly, the LTSS needs of people with disabilities vary widely given the diversity in their impairments and family circumstances.

What Kinds of Services Are Considered LTSS?

The costs of new LTSS benefits will depend on which services policymakers elect to include in the benefits package. LTSS are often divided into two major categories: services delivered in institutions and those delivered in the community. Some service settings, like assisted living facilities, may appear to fall in between.⁹ Peebles and Bohl (2014) provide a typology of HCBS that includes case management, day services, round-the-clock services, supported employment, nursing, home-delivered meals, home-based services, caregiver support, other behavioral and mental health services, other health and therapeutic services, services supporting participant direction, participant training, nonmedical training, equipment and modifications, and community transition services.

Some people confuse home care—which is almost always considered LTSS—with home health care, post-acute care medical care services provided at home and already covered by Medicare, Medicaid, and many private health insurance policies, which most analysts consider distinct from LTSS. The confusion is understandable, but the more medical in nature the services, the less likely they would be included in a new single-payer LTSS benefit.¹⁰

How Many People Receive LTSS?

People needing LTSS receive a mix of services from paid providers and unpaid help from family and friends. Estimates of how many people receive LTSS vary widely and depend on whether one examines services on a given day, in a given week or month, or over a full year. Estimates also depend on which services one includes.

FORMAL (PAID) SERVICES

Under current law, an estimated 8.3 million people of all ages used formal LTSS in 2016, according to the definition in Harris-Kojetin and colleagues (2019).

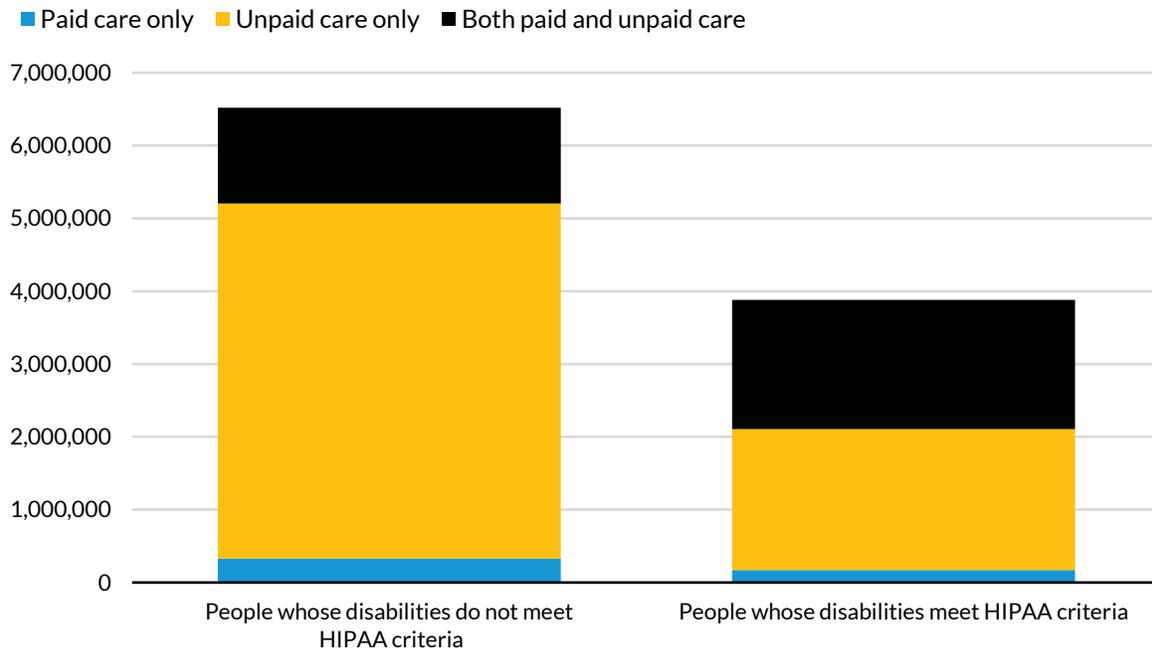
Eiken (2017) estimated that 5.2 million people used some type of Medicaid-financed LTSS in 2013, with 3.7 million receiving at least some HCBS and the remainder using at least some institutional care. About 16 percent of the 5.2 million were children and youth, 40 percent were adults ages 21 through 64, and 45 percent were older adults.

UNPAID CARE

As noted, estimates of the number of people giving and receiving care vary widely. Most estimates are limited to the population age 65 or older but all indicate that regardless of age, people living in the community far more commonly receive unpaid care than formal care (Houser, Gibson, and Redfoot 2010; Kaye, Harrington, and LaPlante 2010; Willink et al. 2017). Most people who receive paid care in the community also receive some unpaid care. Figure 2, based on National Health and Aging Trends Study data, reports that more aged home care users have disabilities falling below the HIPAA threshold than above it. Those with disabilities below this threshold use a smaller share of paid formal care than unpaid family care but receive the majority of both types of care.

FIGURE 2

Estimated Number of People Ages 65 and Older in the Community Receiving Care, by Type of Care, 2015



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Source: Tabulations by Brenda Spillman from the 2015 National Health and Aging Trends Study.

Notes: HIPAA = Health Insurance Portability and Accountability Act. Those in assisted living are considered to be receiving paid help.

Who Provides LTSS under Current Law?

THE LTSS WORKFORCE

Estimates of formal LTSS caregivers also vary, posing additional challenges for considering potential costs of expanded LTSS programs. PHI (2017) estimates the US direct care labor force at 2 to 4.5 million workers. Under current law, many LTSS providers receive low pay and limited employee benefits to perform work that is both physically and emotionally arduous, and for which they often feel a lack of appreciation and respect (Osterman 2017). Care recipients may have impairments that make it difficult for them to communicate, and some may be aggressive because of their disabilities (Zhao et al. 2016). Some agencies face shortages of home care workers, and turnover in this profession is rapid (Espinoza 2019; Home Care Pulse 2019).

FAMILY CAREGIVERS

One recent study reports that the estimated number of caregivers for people with disabilities ranges from 21 to 40 million, depending on the data source used (Reinhard et al. 2019). By some estimates, roughly half of caregivers assist a person whose disabilities meet or exceed the HIPAA threshold (Favreault and Spillman 2018). Reinhard and colleagues (2019) and Spillman and colleagues (2014) estimate that family caregivers provide tens of billions of hours of unpaid care annually. Studies consistently show that people with the highest needs receive more unpaid care in a typical week or month than people with lower needs.

Studies that formally value care reach different estimates depending on the prices they attach to each hour of care. Most conclude that families' contributions are large—ranging from \$400 to \$500 billion dollars, considering care recipients at all age ranges and disability levels (Reinhard et al. 2019),¹¹ to about half that if considering just older-age and dementia care (Hurd, Martorell, and Langa 2015).¹²

Unmet Need under Current Law

Several sources suggest that under existing financing arrangements and eligibility levels, many people's LTSS needs are not fully met. Recent literature on the older population suggests millions of people with limitations experience adverse consequences—including needing to stay in bed, going without groceries, and having soiled clothing—associated with unmet LTSS needs (Allen, Piette, and Mor 2014; Freedman and Spillman 2014). People with high LTSS needs also face economic hardships and are more likely to report trouble paying for food, rent, utilities, medical care, and prescription drugs (Willink, Davis, et al. 2019). Literature in this area often suggests that unmet need is a greater problem for those with the greatest needs, both functionally and economically (Freedman and Spillman 2014; Willink, Kasper, et al. 2019). Over 700,000 people were estimated to be on waiting lists for Medicaid HCBS waiver programs in 2017, and these lists are disproportionately composed of people with intellectual and developmental disabilities (Musumeci, Chidambaram, and O'Malley Watts 2019a; O'Malley Watts and Musumeci 2018).¹³

Who Pays for LTSS under Current Law?

The question of who pays for LTSS is inextricably linked to what services one considers LTSS. Analysts can come to very different conclusions about who pays for LTSS depending on which types of services and providers they include in their estimates.¹⁴ Particularly thorny issues are treatment of Medicare-financed home health care and care in skilled nursing facilities and residential settings other than

nursing homes. Generally, Medicare does not cover LTSS if that is the only service a beneficiary needs.¹⁵ That leads some analysts to exclude it from all estimates (Hado and Komisar 2019), whereas other analysts include it fully or only partially.

By virtually all estimates, Medicaid is the primary public payer for LTSS. Families are another important payer, and their role is underestimated because health statistics typically omit the types of paid care that families most commonly finance out of pocket, like residential care (Hartman, Kornfeld, and Catlin 2010) or private-pay home care, as opposed to agency care (Newquist, DeLiema, and Wilber 2015; Seavey and Marquand 2011).

The LTSS Payer Typology Used in This Study

In this study, we typologize LTSS payers in a more stylized way than we and other authors have in prior work. For ease of presentation, we focus on three components that would shape new costs to the federal government and participation levels in single-payer health care plans that include new LTSS benefits: family out-of-pocket spending, Medicaid spending, and unpaid family care.

Following Hado and Komisar (2019), we first exclude any services covered by Medicare.¹⁶ Further, to simplify, we classify services paid by private long-term care insurance as paid by households, given that households pay premiums for the coverage.¹⁷ Were Congress to enact a universal LTSS program within a single-payer program, lawmakers would need to determine how existing contracts would integrate with the new program.¹⁸ Next, we follow Eiken and colleagues (2018) when determining how to quantify Medicaid LTSS caseloads and spending. The estimated amount of LTSS Medicaid delivers varies across sources, and states' increased use of managed care for LTSS further complicates estimation.

Estimating out-of-pocket medical expenses for LTSS is challenging. In valuing out-of-pocket LTSS, we attempt to include care costs families incur in private transactions that the National Health Expenditure Accounts may not capture (Newquist, DeLiema, and Wilber 2015; Seavey and Marquand 2011).¹⁹ Given that the LTSS proposals we describe below do not give much detail on potential coverage for noninstitutional residential care options, we follow reports from the National Health Expenditure Accounts and exclude most residential care costs not financed by Medicaid (Hartman, Kornfeld, and Catlin 2010).²⁰

Finally, we exclude from our calculations care currently provided by the Veterans Administration and area agencies on aging, which are funded under the Older Americans Act under current law.²¹

Single-Payer and Other Legislative Proposals That Include Large Changes to LTSS Financing

Table 1 summarizes the eligibility criteria and benefit levels of selected recent proposals to expand LTSS coverage in broader health reform plans. Benefit criteria are often defined based on needing assistance with performing ADLs and IADLs. Where legislators specify these, the table describes how new benefits would integrate with current-law arrangements, whether and how programs would implement point-of-care cost sharing, and the proposals' financing. However, those that specify financing apply it to the full package of health care benefits, not just the LTSS component.²²

The table reveals that some recent single-payer proposals introduced in Congress do not explicitly enumerate eligibility criteria for LTSS, but they intend to markedly expand coverage. Some proposals also contain relatively limited information about benefit packages. This paucity of detail suggests these proposals are best considered the initiation of legislative discussion, focused on goals rather than a final legislative product.

By contrast, previous initiatives in Hawaii and Washington State and Representative Frank Pallone's (D-NJ) discussion draft for a federal program are more fully developed.²³ These initiatives used more precise and restrictive criteria for benefits, often closely related to the disability definition specified in HIPAA. Notably, these earlier plans also limit benefits; Washington's new program limits LTSS payments to a lifetime total of \$36,500 (indexed), and Representative Pallone's plan limits LTSS to approximately five hours of service per day after a two-year waiting period. Similarly, under current law, most state Medicaid programs primarily provide services to those with relatively high levels of need and may scale services available based on disability level (Mollica and Reinhard 2005).

TABLE 1

Descriptions of LTSS Benefits in Recently Proposed Legislation

Proposal/ program	Services and benefit form?	Eligibility trigger?	Integration with other programs?	Provider rates?	Financing? Prefunding?	Cost sharing?
Medicare for America Act of 2019, H.R. 2452, 116th Cong. (2019), proposed by DeLauro	Starting in 2023, provide “home and community-based LTSS benefits.” This includes the following: daily living supports needed to live, work, and participate in the community and all HCBS under any Medicaid state plan or waiver, including home health aides/homemakers, personal attendant care services, hospice, nursing care, direct support professionals, and medical social services; care coordination, including case management, support brokerage, and fiscal intermediary services; short-term inpatient care, including respite and pain control care; behavioral HCBS, including assertive community treatment, peer support services, supported employment, and supported housing wraparound; intensive care coordination, including case management, private-duty nursing, respite services at home or in community, and support services to transition from institutional settings. Families can provide paid services.	Person is unable to perform, without substantial assistance, at least one ADL included in HIPAA, or requires substantial assistance with one or more of the following: communication; social interaction; learning; self-management; self-care; or impairments that affect capacity for social or economic participation.” Note that reference to the Internal Revenue Code of 1986 implies disability needs must have lasted 90 days. Eligibility would depend on HHS secretary decisions about where plan is available.	States must maintain effort (adjusting for GDP growth) or lose access to some block grants. Program phases in so that people enrolled in qualified coverage (including employer plans, CHIP, VA, TRICARE, others) in early program years can opt out. Receiving LTSS benefits would not disqualify an individual from other assistance.	HHS secretary sets payment rates based on current Medicare rates and as otherwise needed for adequate access.	Proposes to pay for overall package, not just LTSS, as follows: Sunset TCJA; 5% surtax on AGI above \$500,000; increase Medicare payroll tax and investment income tax; increase excise taxes on tobacco, alcohol, and sugar-sweetened drinks.	Has no point-of-care cost sharing for those with income below 200% of FPL; for the overall program, premiums (8% of household income) and overall sliding-scale health deductible are based on income relative to poverty.
Medicare for All Act of 2019, H.R. 1384, 116th Cong. (2019), proposed by Jayapal	Long-term care, treatment, maintenance, or services needed to support ADLs and IADLs, including all LTSS available under § 1915 of the Social Security Act (42 U.S.C. 1396n), HCBS, and additional services and supports the HHS secretary identifies to support people with disabilities to live, work, and participate in their communities. Specifically mentions coverage for both institutional and	Person has “functional limitation in performing one or more ADLs; or requires a similar need of assistance in performing IADLs due to cognitive or other impairments.” ADLs specified include: eating, toileting,	Employers should not offer insurance that duplicates. VA and Indian Health Service unchanged; other programs sunset.	References Medicare rates as a starting point for global health budget.	Not specified.	No cost sharing, including deductibles, coinsurance, copayments, or similar charges, and no balance billing. (Some cost sharing for

Proposal/ program	Services and benefit form?	Eligibility trigger?	Integration with other programs?	Provider rates?	Financing? Prefunding?	Cost sharing?
	noninstitutional services, prioritizing noninstitutional care where possible.	grooming, dressing, bathing, transferring.				prescription drugs.)
Medicare for All Act of 2019, S. 1129, 116th Cong. (2019), proposed by Sanders	Home- and community-based LTSS provided in accordance with requirements under 42 CFR § 441.530 and § 441.710, including services described in paragraphs (7), (8), (13), (19), and (24) of § 1905(a) of the Social Security Act (42 U.S.C. 1396d(a)); ^a uses HCBS definitions from § 1915 of the Social Security Act, described in subsection (c)(4)(B), which includes habilitation services defined in subsection (c)(5); self-directed HCBS, as in subsection (i); self-directed personal assistance services, as defined in subsection (j)(4)(A); and HCBS attendant services and supports described in subsection (k).	Does not specify LTSS criteria, instead using broader test for health care that it should be “medically necessary or appropriate for the maintenance of health or for the diagnosis, treatment, or rehabilitation of a health condition.”	Medicaid would continue to cover institutional care. States must maintain effort (indexes eligibility parameters by medical CPI) or lose federal payments; target maintenance of effort adjusts for demographics, state-level health cost growth, and offsets from new HCBS. No change to VA LTSS.	Payment rates would be similar to Medicare rates.	Offsets from current programs and details to be specified.	Does not specify LTSS but generally calls for no cost sharing, except for prescription drugs, and then only for those with income over 200% of FPL and with an out-of-pocket maximum of \$200 (indexed).

Sources: Medicare for America Act of 2019, H.R. 2452, 116th Cong. (2019); Medicare for All Act of 2019, H.R. 1384, 116th Cong. (2019); Medicare for All Act of 2019, S. 1129, 116th Cong. (2019).

Notes: LTSS = long-term services and supports. HCBS home- and community-based services. ADL = activities of daily living. HIPAA = Health Insurance Portability and Accountability Act. HHS = US Department of Health and Human Services. GDP = gross domestic product. CHIP = Children’s Health Insurance Program. VA = US Department of Veterans Affairs. TCJA = Tax Cuts and Jobs Act. FPL = federal poverty level. AGI = adjusted gross income. IADL = instrumental activities of daily living. CFR = Code of Federal Regulations. CPI = consumer price index. Text of legislation/proposals edited for length and clarity.

^a These include home health care, private duty nursing, case management, personal care, home- and community-based (including self-directed), and attendant services.

The Medicare for All Act of 2019,²⁴ introduced in February 2019 by Representative Pramila Jayapal (D-WA) and cosponsored to date by 118 other representatives, bases eligibility for LTSS benefits on functional limitations in at least one ADL or equivalent need based on other limitations. It proposes a comprehensive LTSS benefit package, but without complete specifications. The proposal's text indicates that the broad goal is comprehensive coverage for both institutional LTSS and HCBS, prioritizing the latter. The bill would defer many decisions, including eligibility and assessment criteria, residency requirements, annual benefit package adjustments, and quality standards, to the secretary of the Department of Health and Human Services, who would be required to consult with an LTSS advisory commission. The proposal explicitly states that there would be no beneficiary cost sharing, specifically no balance billing or copayments, deductibles, or similar charges. This is consistent with the proposal's approach to traditional health care benefits.

The LTSS provisions of the Medicare for America Act of 2019,²⁵ introduced in May 2019 by Representative Rosa DeLauro (D-CT) and cosponsored to date by 25 other representatives, would greatly expand access to HCBS. Those with either one ADL limitation or requiring substantial assistance with communication, social interaction, learning, self-care, and self-management would be eligible for HCBS. Further, those requiring substantial assistance with "impairments that affect capacity for social or economic participation" could also be eligible. As table 1 indicates, program benefits would cover a wide spectrum of HCBS, including home health, home care, respite, case management, transitional, and other services. The legislation emphasizes a model of serving people in the community first, highlighting self-direction.²⁶

Senator Bernie Sanders (I-VT) introduced the Medicare for All Act of 2019 in April 2019.²⁷ To date, 14 other senators have signed on as cosponsors, including four former candidates for the Democratic Party presidential nomination: Senators Cory Booker (D-NJ), Kirsten Gillibrand (D-NY), Kamala Harris (D-CA), and Elizabeth Warren (D-MA). Sanders's proposal does not specify the disability eligibility criteria for LTSS benefits, referring only broadly to services for "maintenance of health" and "treatment or rehabilitation of a health condition." The legislation focuses only on HCBS, leaving existing Medicaid benefits for institutional care intact. States are prohibited from reducing access to institutional care for LTSS under their Medicaid programs, and adjustments are made for inflation and future population changes, including aging. The proposed HCBS benefit uses Medicaid standards as a starting point. The broader text suggests cost sharing is only required for prescription drugs, implying no point-of-care cost sharing for HCBS.

Parameters and Intermediate Assumptions for the Three Stylized Options for Single-Payer LTSS Programs

We project the cost and distributional effects of stylized versions of three proposals that vary in the generosity of their benefit packages and expansiveness of their disability criteria, as suggested by the proposed legislation. We anchor the projections to those from prior literature where possible but must make assumptions because of limitations in the data and prior literature.

Option 1: Expanded HCBS access based on HIPAA standards. Our first option simulates a benefit that would provide extensive HCBS without cost sharing for anyone, regardless of income or assets, whose disabilities meet HIPAA standards: two or more ADL limitations or need for supervision due to severe cognitive impairment. The maximum benefit would be set at \$150 per day in 2020 and then would grow with inflation;²⁸ at median national prices, this would now amount to about seven hours of home care per day.²⁹ This daily benefit aligns with reports of the average level of coverage which private long-term care insurance buyers purchased in 2015 (LifePlans 2017). Medicaid would continue to cover certain people in institutional settings, as under current law. We assume the benefit structure is service reimbursement, not cash, and therefore expect lower utilization (Armentrout and Trapnell 2019; Giese and Schmitz 2015).

This stylized lowest-cost option resembles key aspects of Sanders's Medicare for All bill, which assumes the Medicaid program would continue covering institutional care. However, this option is far more limited than the LTSS program outlined in Sanders's proposal. Unlike the Sanders plan, which specifies neither eligibility criteria nor service limits, this option bases eligibility criteria on current practice (HIPAA rules) and imposes dollar limits on services, consistent with typical long-term care insurance policies and other proposed legislation. Our stylized proposal resembles the time-unlimited home health benefit in a recent National Academy of Social Insurance report (Veghte et al. 2019), but with a higher maximum daily benefit. It also resembles, but is more generous than, our earlier home care analyses of prior proposals by Sanders (Holahan et al. 2016). The validation discussion below describes differences between our current and prior analyses.

Option 2: Expanded HCBS access with an institutional benefit. This option builds on option 1 and extends an equivalent benefit to people in institutions. Families paying out of pocket, either fully or partially, for nursing home care can receive up to \$150 per day toward those costs.³⁰ We consider this an expanded benefit because some prior single-payer bills have included institutional care as part of the benefits package, and it is helpful to illustrate and isolate the effects of an institutional benefit on an already expanded system.³¹ The median daily rate for a semiprivate room in a nursing home is now

about \$247 per day (Genworth 2019), so the new LTSS program would cover more than half of median nursing home costs for a person paying out of pocket, with some variation by state of residence.³²

Option 3: Expanded HCBS access based on less strict standards. We chose to model the final option after recent single-payer bills, including the broad intentions expressed in Representatives DeLauro's and Jayapal's bills to expand eligibility for public LTSS. This third option builds on option 2 and further expands the HCBS benefit, still subject to the daily limit, to those whose disabilities fall below the HIPAA threshold. This option would provide services to people needing substantial assistance because of one or more ADL or IADL limitations. Under this option, nursing home care would also be covered without cost sharing.

Our Approach to Modeling the Stylized Plans

Intermediate Assumptions for All Three Plans

Because recent proposals to include LTSS in single-payer health care plans are more generous than those previously evaluated, our ability to use existing government and private long-term care insurance industry data to inform these assumptions is limited.³³ Further, most of these proposals discuss benefit levels only generally, requiring us to make many assumptions in our analyses. However, our prior analyses of a comprehensive cash LTSS benefit for those with HIPAA-level LTSS needs (Favreault, Gleckman, and Johnson 2015) and an unlimited home health benefit in a recent National Academy of Social Insurance report (Armentrout and Trapnell 2019; Veghte et al. 2019) provide us with starting points.

As in prior work, we begin by assuming that the difference between total LTSS needs and total paid care consumed under current law provides one meaningful indicator of the potential demand for paid LTSS under an expanded system. (We measure these using reports in high-quality household survey data.³⁴) Currently, the difference between need and service use is a combination of care from family caregivers and unmet need.

Defining LTSS and components of the benefit package. As table 1 indicates, the service packages described in the single-payer proposals are potentially broad, including a wide mix of services that help recipients with ADLs. Some proposals, especially those sponsored by Representatives DeLauro and Jayapal, also include services designed to maximize social integration more broadly, including employment. Different choices about how far to extend these benefit packages could lead to markedly different estimates of who receives and pays for LTSS.

We project costs only for services focused on meeting daily personal needs, like bathing, dressing, eating, transferring, and toileting, or providing supervision for those whose health and safety require it (e.g., for those with severe cognitive impairment), whether delivered at home in the community or in traditional, long-stay nursing homes. To avoid double counting, we exclude many services that resemble LTSS but that Medicare currently covers, such as home health care or care in a skilled nursing facility for rehabilitation after an injury, joint replacement, or illness. We exclude the cost of room and board for those in residential care/assisted living but include it for those in long-stay nursing homes. We attempt to include potential reimbursements for services paid directly to providers (rather than through an intermediary, like a home care agency) under current law but acknowledge we can do this only crudely.³⁵

Provider payment rates. Because the legislative proposals clearly intend to increase access to formal LTSS, we assume payment rates must increase to meet the higher demand for providers, given challenges in meeting even current demand—and, some argue, costs—at current Medicaid and private payment rates (Fossberg 2019; Hansen Hunter 2018; O’Keeffe, O’Keeffe, and Bernard 2003). Some proposals defer the choice of how to adjust provider payments to the secretary of the Department of Health and Human Services. Several proposals that specify rates refer to Medicare rather than Medicaid rates, but how to interpret this in the LTSS context is unclear, because most new program services would not map directly to comparable Medicare services (MedPAC 2017, 2018). We assume payment rates would increase relative to current law to meet increased demand and would vary across states and localities. The daily maximum HCBS benefit we model implies price increases could potentially be partly offset by service reductions.

Supplementing unpaid family care and reducing unmet need. We hypothesize that if subsidized LTSS were more widely available, roughly half of families of people with the most severe disabilities would use paid care to supplement or substitute for family care.³⁶ For option 3, we assume a somewhat lower share of families of people with less severe disabilities who are newly eligible would supplement unpaid care. We assume families would use more paid care to reduce unmet need and caregiver burden, potentially allowing family caregivers to devote more time to providing companionship rather than direct, hands-on ADL and IADL help (Cohen, Weinrobe, and Miller 2000); of course, managing interactions with paid helpers can also require significant effort from family caregivers. Still, family responses will likely be diverse and sensitive to income (Goda, Golberstein, and Grabowski 2011; Golberstein et al. 2009; Li 2005; Li and Jensen 2011; Stabile, Laporte, and Coyte 2006). Many families would choose not to receive services for various reasons, including to remain as independent as possible for as long as possible and, in some cases, to avoid having strangers in their homes (Levine and

Lee 2017; NORC 2018). Because of the lack of precedent, any assumption will be speculative. We vary these assumptions in sensitivity analyses.

How much families supplement and substitute unpaid care with formal care would reflect the cost, flexibility, and quality of new services (i.e., the cheaper, more flexible, and higher quality the services, the greater the demand for them, consistent with prior literature).³⁷ Based on the limited cost sharing,³⁸ we assume extensive, but not full, take-up of new services. This is consistent with other recent projections, actuarial experience data from the private long term-care industry, and prior literature. Broyles and colleagues (2010) directly link copayments to participation in home care and assume a fourfold increase in home care use—from roughly 15 percent of the severely disabled, community-dwelling population to 60 percent—for programs with zero copayment, still assuming some will continue to rely solely on unpaid family care.³⁹ Similarly, Liu and colleagues (2018) assume that half of unpaid family care will be supplemented and supplanted in their base analyses of LTSS under a single-payer plan. More conservatively, Armentrout and Trapnell (2019) assume near-complete benefit take-up for those with significant disabilities in a universal home care program. Because the programs we model are universal rather than voluntary, we need not address adverse selection. However, we assume service intensity would increase with severity of disability.

In sum, we expect that under the broader eligibility criteria of the proposed LTSS programs, formal LTSS use will increase markedly, and both family burdens and unmet needs will fall. The reductions will not be uniform, because some people will not participate.

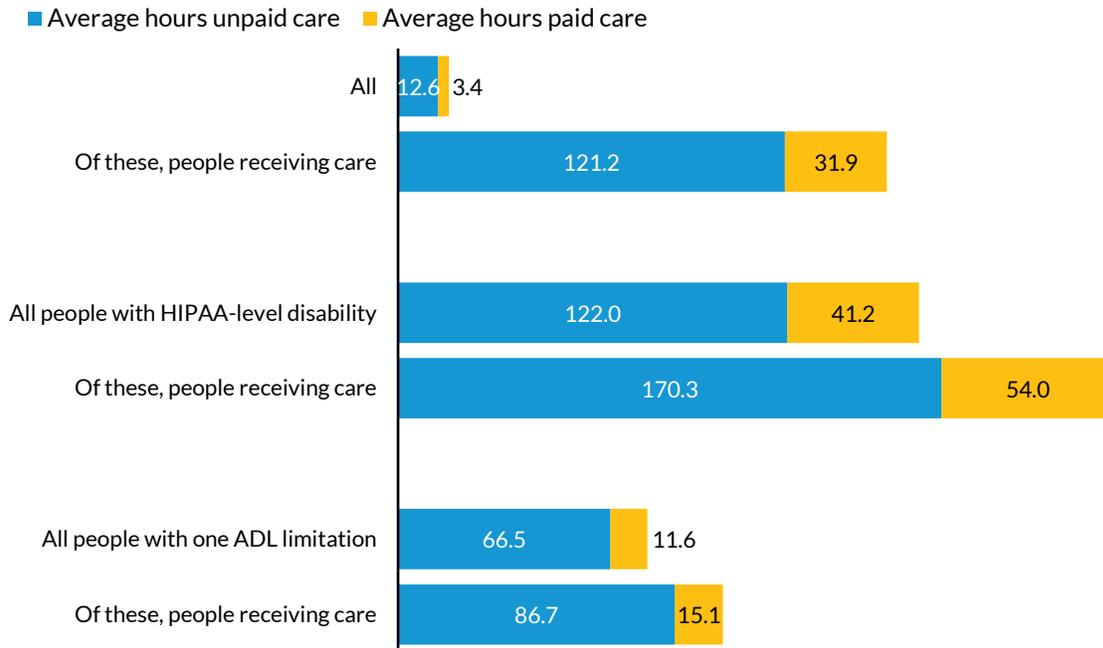
Intensity of service. We assume intensity of service is proportional to LTSS need and current-law use (figure 3).⁴⁰ As figure 3 shows, people ages 65 and older with a HIPAA-level disability receive close to full-time help: about 160 hours per month on average, or nearly 40 hours per week. Of that average, the share receiving any type of help averages about 224 hours of home care per month, over 7 hours every day, including weekends. For people with just one ADL limitation, care use is about half as high.

Under intermediate assumptions for these new benefits, the base analyses for the program that requires HIPAA-level disability thus assume up to seven days of home care service for the high-need population subgroups and six days of service for others.⁴¹ For option 3, expanded access based on less strict eligibility criteria, we base intensity on estimated multiples of existing utilization. As figure 3 shows, people whose disabilities meet a lower threshold use less care on average (about half as much, and a lower share paid), so we assume they use roughly one-third of the services people with higher-level disabilities use. We assume the number of beneficiaries, regardless of age, may increase to as

much as 35 percent (based on figure 1), with a service intensity-weighted increase in spending of approximately 20 percent (combining figures 1 and 3).

FIGURE 3
Average Hours of Paid and Unpaid Home Care Received per Month among People Ages 65 and Older Living in the Community, by Disability Level and Care Receipt, 2015

Older adults receiving care averaged over 150 hours of care per month, but this varies by presence and type of disability



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Source: Tabulations by Melissa Favreault from the 2015 Health and Retirement Study.

Notes: HIPAA = Health Insurance Portability and Accountability Act. ADL = activities of daily living. All people with one activity of daily living limitation are not severely cognitively impaired. Each “all” category includes people who did not use any care.

State maintenance of effort. Our analyses assume that the federal government takes on the portion of Medicaid LTSS costs states cover under current law, except under option 1 where states continue to provide institutional care now provided by Medicaid. Readers can use the estimated changes to states’ costs to approximate the effects of requiring states to maintain effort on the stylized proposals. However, these stylized estimates assume little change in states’ behaviors. Under option 1, a universal home care benefit with few limits or restrictions could incentivize states to shift people from institutions to HCBS; a less mechanical interpretation of the state-federal mix may thus be warranted.

Administrative costs. We assume administrative costs of 6 percent for the program.

Sensitivity Analyses for Each Option

We integrate sensitivity analyses into our estimation of costs. Given the many unknown factors, we supplement our best-guess projections with higher- and lower-cost projections for each option. For example, in our high-cost projection, we integrate more significant behavioral response, with more families opting to participate and receive formal services. In the low-cost option, we assume supply constraints limit utilization. Liu and colleagues (2018) use sensitivity analyses in their estimates for New York state. We have similarly used sensitivity analyses in our earlier analyses of tax credits and respite benefits for LTSS (Favreault and Spillman 2018), and other analyses used similar sensitivity tests when they modeled a life care annuity (Murtaugh, Spillman, and Warshawsky 2001).

Our sensitivity analyses focus on four major factors that could affect costs: (1) families' decisions to supplement unpaid care with paid care, (2) disability prevalence and disability "inflation" (sometimes called "ADL creep" and akin to "upcoding" in other health care contexts), (3) service days per week,⁴² and (4) the labor market's ability to meet demand for paid care workers at proposed or assumed reimbursement rates.⁴³ After the baseline year, we also factor in uncertainty about how quickly costs would grow. Combining these factors, we arrive at two sensitivity analyses that bracket our best-guess projections:⁴⁴

- **Lower-cost.** Provider shortages are so intense that not everyone can receive the services they prefer. Disability rates are on the lower end of published estimates and screening of disability level is stringent, so there is no net disability inflation. Only about a quarter of families that provide unpaid care to family members with severe disabilities under current law decide to supplement unpaid care with paid, formal care under the proposal; only about 20 percent of family members of those with less severe disabilities supplement unpaid care with paid care. Fewer beneficiaries receive full-week service, and more receive services five or fewer days per week.
- **Higher-cost.** There are no provider shortages, so almost everyone can receive the services they prefer. Disability rates are on the higher end of published estimates and disability inflation is significant. About three-quarters of families decide to supplement unpaid care with paid care at high disability levels, and about 60 percent of families do so at lower disability levels in option 3. We assume more people take a full-week benefit than under the intermediate assumptions, where only the highest-need beneficiaries receive services seven days per week.

Combining these factors, we arrive at a range of possible costs for each option. Because we have endeavored to be conservative with our intermediate assumptions, the low- and high-cost scenarios are

not symmetrical (i.e., the absolute differences are greater between the low-cost and intermediate scenarios than between the high-cost and intermediate scenarios). Option 3 is closer to symmetrical because of the greater uncertainty and lack of independent projections.

Methods and Data

To generate our estimates, we synthesize information from a range of data sources, including published reports (Eiken 2017; Eiken et al. 2018; Harris-Kojetin et al. 2019; Kaye, Harrington, and LaPlante 2010; Musumeci, Chidambaram, and O'Malley Watts 2019a, 2019b; NAIC 2019; Peebles et al. 2017); tabulations of data from the Health and Retirement Study, Medicare Current Beneficiary Survey, National Health Interview Survey, and National Health and Aging Trends Study;⁴⁵ and simulations from the Dynamic Simulation of Income Model, or DYNASIM, the Urban Institute's simulation model designed to project the distributional consequences of retirement and aging issues, including LTSS needs and expenditures (Favreault, Gleckman, and Johnson 2015; Favreault, Smith, and Johnson 2015).⁴⁶

We require so many different sources because datasets cover different age groups, populations, and payers. More fundamentally, gaps in data on LTSS needs and use even under current law exacerbate an already complex task (Favreault and Tumlinson 2019).

The estimates are based on current utilization patterns for paid services and unpaid care and recent trends in severe cognitive impairment and ADL limitations. In the middle (intermediate, best-guess) case, the estimates assume about half of care currently provided by unpaid family caregivers would be supplemented or replaced by paid care under the proposal.

Because we completed these analyses in 2019, our estimates do not include any demographic or economic effects of the novel coronavirus pandemic.

Results

Table 2 presents one-year spending projections for current law and the three stylized options, including the low- and high-cost sensitivity analyses, in 2020. The table breaks out new costs for the federal government and then identifies offsets through federal Medicaid savings and reductions in families' out-of-pocket costs. Table 3 shows a subset of the cost information from table 2 over 10 years (2020–29), and figure 4 summarizes the results for the intermediate assumptions.

TABLE 2

Total Spending for Three Options That Expand LTSS Access, Including Low- and High-Cost Sensitivity Analyses, 2020

Billions of dollars

	Current Law	Option 1 (Base) Expanded HCBS access based on HIPAA standards: Home care benefit with generous daily limit (up to \$150/day) for those with disabilities at or above HIPAA trigger level and no cost sharing			Option 2 Expanded HCBS access based on HIPAA standards with an institutional benefit: Home care benefit in base plus cash equivalent for nursing home for those incurring out-of-pocket LTSS expenses beyond home care			Option 3 Expanded HCBS access based on less strict standards: Comprehensive LTSS with no cost sharing, including for those below HIPAA trigger level with at least one ADL limitation		
		Low-cost	Best-guess (intermediate)	High-cost	Low-cost	Best-guess (intermediate)	High-cost	Low-cost	Best-guess (intermediate)	High-cost
Total	309	443	547	586	454	564	599	473	630	773
Federal government	105	355	460	499	445	555	590	473	630	773
Medicaid	105	49	49	49	0	0	0	0	0	0
Single-payer plan	0	306	411	450	445	555	590	473	630	773
State government										
Medicaid	92	43	43	43	0	0	0	0	0	0
Households	112	45	45	45	9	9	9	0	0	0
Net savings to households on current-law spending	–	67	67	67	103	103	103	112	112	112
Ratio of total spending to current-law total spending	1.0	1.4	1.8	1.9	1.5	1.8	1.9	1.5	2.0	2.4
Ratio of federal spending to current-law federal spending	1.0	3.4	4.4	4.8	4.3	5.3	5.6	4.5	6.0	7.2
New formal services for households	–	134	238	277	145	255	290	164	321	447
Total change for households (new services plus reduced out-of-pocket costs relative to current law)	–	201	306	345	248	358	393	276	433	559

Sources: Author’s calculations from the Dynamic Simulation of Income Model supplemented with information from the Health and Retirement Study, National Health and Aging Trends Study, National Health Interview Survey, and Medicaid Current Beneficiary Survey and published statistics (Eiken 2017; Eiken et al. 2018; Musumeci, Chidambaram, and O’Malley Watts 2019a, 2019b; NAIC 2019; Peebles et al. 2017).

Notes: LTSS = long-term services and supports. HCBS = home- and community-based services. HIPAA = Health Insurance Portability and Accountability Act. ADL = activity of daily living. Cells are marked with – when the row does not apply to the column head. Our LTSS concept includes only services delivered in the community or in traditional, long-stay nursing homes that focus on meeting daily personal needs, like bathing, dressing, eating, transferring, and toileting, or providing supervision for those whose health and safety require it (e.g., for those with severe cognitive impairment). When evaluating Medicaid, we include any services that Eiken and colleagues (2018) include. For other payers, needs arise because of a disability that has lasted at least 90 days. We exclude Medicare-covered services, such as postacute care or home health, and care the Veterans Administration provides. We also exclude other types of services delivered in residential settings, like rehabilitation for substance use disorders/addiction or mental health alone. We include care costs that are part of residential care (assisted living) but exclude room and board; we include room and board in traditional long-stay nursing homes. We attempt to include care costs families incur in private transactions; see Newquist, DeLiema, and Wilber (2015) or Seavey and Marquand (2011) for discussion. For ease of presentation, we consider services paid for by private long-term care insurance as paid by households, given that households paid premiums for the coverage. Savings to states are equal to the current law state Medicaid spending estimate minus the projected option state Medicaid spending, where option 1 assume states are required to maintain effort for institutional care and options 2 and 3 assume states are not required to maintain any Medicaid LTSS effort.

TABLE 3
Ten-Year Spending Estimates for Three Options That Expand LTSS Access, Including Low- and High-Cost Sensitivity Analyses, 2020–29
Trillions of dollars

Current Law	Option 1 Expanded HCBS access based on HIPAA standards: Home care benefit with generous daily limit (up to \$150/day) for those with disabilities at or above HIPAA trigger level and no cost sharing			Option 2 Expanded HCBS access based on HIPAA with an institutional benefit: Home care benefit in base plus cash equivalent for nursing home for those incurring out-of-pocket LTSS expenses beyond home care			Option 3 Expanded HCBS access based on less strict standards: Comprehensive LTSS with no cost sharing, including for those below HIPAA trigger level with at least one ADL limitation			
	Low-cost	Best-guess (intermediate)	High-cost	Low-cost	Best-guess (intermediate)	High-cost	Low-cost	Best-guess (intermediate)	High-cost	
Total LTSS spending		6.8								
New formal LTSS	–	1.6	3.0	3.6	1.7	3.2	3.7	2.0	4.0	5.8

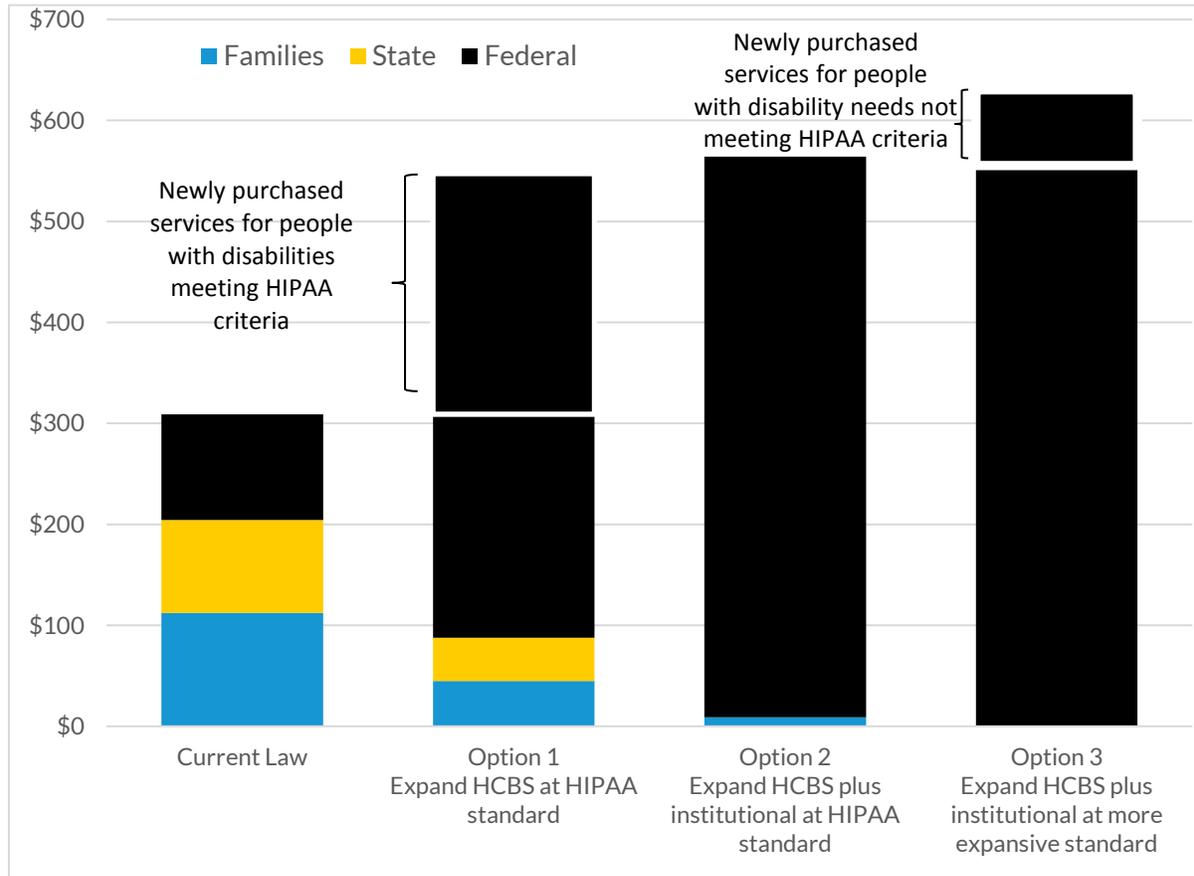
Sources: Author’s calculations from the Dynamic Simulation of Income Model supplemented with information from the Health and Retirement Study, National Health and Aging Trends Study, National Health Interview Survey, and Medicaid Current Beneficiary Survey and published statistics (Eiken 2017; Eiken et al. 2018; Musumeci, Chidambaram, and O’Malley Watts 2019a, 2019b; NAIC 2019; Peebles et al. 2017).

Notes: LTSS = long-term services and supports. HCBS = home- and community-based services. HIPAA = Health Insurance Portability and Accountability Act. ADL = activity of daily living. Cells are marked with — when the row does not apply to the column head. A cell is empty when we have chosen to omit estimates because of measurement challenges. Our LTSS concept includes only services delivered in the community or traditional, long-stay nursing homes that focus on meeting daily personal needs, like bathing, dressing, eating, transferring, and toileting, or providing supervision for those whose health and safety require it (e.g., for those with severe cognitive impairment). When evaluating Medicaid, we include any services that Eiken and colleagues (2018) include. For other payers, needs arise because of a disability that has lasted at least 90 days. We exclude Medicare-covered services, such as postacute care or home health, and care the Veterans Administration provides. We also exclude other types of services delivered in residential settings, like rehabilitation for substance use disorders/addiction or mental health alone. We include care costs that are part of residential care (assisted living) but exclude room and board; we include room and board in traditional long-stay nursing homes. We attempt to include care costs that families incur in private transactions; see Newquist, DeLiema, and Wilber (2015) or Seavey and Marquand (2011) for discussion. For ease of presentation, we consider services paid for by private long-term care insurance as paid by households, given that households paid premiums for the coverage.

FIGURE 4

Family, State, and Federal Costs (in Billions) for Three Options That Expand LTSS Access, 2020

Costs increase largely because of new services that will supplement family caregiving



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Sources: Author’s calculations from the Dynamic Simulation of Income Model supplemented with information from the Health and Retirement Study, National Health and Aging Trends Study, National Health Interview Survey, and Medicaid Current Beneficiary Survey and published statistics (Eiken 2017; Eiken et al. 2018; Musumeci, Chidambaram, and O’Malley Watts 2019a, 2019b; NAIC 2019; Peebles et al. 2017).

Notes: LTSS = long-term services and supports. HCBS = home- and community-based services. HIPAA = Health Insurance Portability and Accountability Act. Our LTSS concept includes only services delivered in the community or traditional, long-stay nursing homes that focus on meeting daily personal needs, like bathing, dressing, eating, transferring, and toileting, or providing supervision for those whose health and safety require it (e.g., for those with severe cognitive impairment). When evaluating Medicaid, we include any services that Eiken and colleagues (2018) include. For other payers, needs arise because of a disability that has lasted at least 90 days. We exclude services that Medicare covers, such as postacute care or home health, and care the Veterans Administration provides. We also exclude other types of services delivered in residential settings, like rehabilitation for substance use disorders/addiction or mental health alone. We include care costs that are part of residential care (assisted living) but exclude room and board; we include room and board in traditional long-stay nursing homes. We attempt to include care costs that families incur in private transactions; see Newquist, DeLiema, and Wilber (2015) or Seavey and Marquand (2011) for discussion. For ease of presentation, we consider services paid for by private long-term care insurance as paid by households, given that households paid premiums for the coverage.

Under current law in 2020, our best guess is that LTSS spending will be about \$309 billion. This estimate is lower than Congressional Research Service estimates of \$366 billion for 2016 because we exclude Medicare postacute spending (Colello 2018); when excluding Medicare, the Congressional Research Service reports 2016 spending of \$286.1 billion.⁴⁷ Conversely, our estimate is higher than AARP's 2017 spending estimate of \$235 billion (Hado and Komisar 2019), which also entirely excludes Medicare postacute spending, because we include an estimate of private-pay home care and portions of residential care.⁴⁸ Under our stylized approach, federal and state governments cover roughly 64 percent of total LTSS spending as defined this way, and households cover about 36 percent.⁴⁹

Under option 1, the new home care benefit would markedly increase both federal and overall spending on LTSS. We project total LTSS spending of about \$547 billion, an increase of over 75 percent from current law. This increase owes to increased service use among current-law HCBS users, the supplementation of large amounts of unpaid care with paid care, and reduced unmet need. Who pays for care would also shift significantly, with households paying about \$45 billion, just 8 percent of total LTSS spending.

Under lower-cost assumptions for this option, with less disability inflation and less supplementation of unpaid family care with paid care, total LTSS spending would increase by about 43 percent, to \$443 billion. Under higher-cost assumptions about disability inflation and utilization, total LTSS spending would increase by about 90 percent, to \$586 billion.⁵⁰

Differences between options 1 and 2 largely owe to accounting. Under option 2, total costs increase only modestly relative to option 1 because we assume, consistent with survey information, that people with severe disabilities strongly prefer to receive services in the community rather than in nursing homes and that demand for nursing home care is relatively inelastic (Grabowski and Gruber 2007). However, federal costs change more significantly when the federal government assumes responsibility for states' Medicaid LTSS programs and residents' out-of-pocket costs for institutional care and HCBS.⁵¹ Under option 2, federal LTSS spending increases by over 500 percent, compared with over 400 percent under option 1. Households' share of spending correspondingly falls to about 2 percent. Requiring state maintenance of effort, as some health care plans would, would more than halve the cost difference between options 1 and 2.

Option 3 would guarantee LTSS in any setting with no cost sharing. Disability thresholds are also set at less restrictive standards, allowing more people to qualify for services. Under intermediate assumptions, we believe total LTSS spending could double, to roughly \$630 billion, because more people would use LTSS, consistent with the historic experience documented in figure 2. However, on

average, benefit users who qualify for LTSS at this level use these services much less. Under lower-cost assumptions, total cost would increase by about 50 percent. Under higher-cost assumptions, projected total spending would be about 240 percent of current-law spending.

Over the 10-year window, projected costs for new services under the universal HCBS benefit (option 1) would be about \$3.0 trillion. When we add the institutional benefit (option 2), this increases to \$3.2 trillion. Expanding the eligible population to include the millions of people with care needs whose disabilities fall below HIPAA standards (option 3) increases the projected costs for new services to \$4.0 trillion. These new services add to the roughly \$3.9 trillion projected for LTSS under current law from 2020 to 2029.

Under option 1, combining these new services with (1) existing federal obligations and (2) transferal of family and state obligations to the federal government increases federal spending by \$5.7 trillion over the 10 years. Adding the institutional benefit raises this to \$7.1 trillion. Expanding the eligible population to include those with disabilities that do not meet HIPAA standards increases federal costs to \$8.1 trillion over this period.

Distributional effects of option 1, the universal HCBS program using HIPAA standards. The new programs would bring new services to many people with LTSS needs. We estimate that about 10 million people with severe disabilities would receive benefits under the program specified in option 1 (table 4). (Consistent with figures 1 through 3, more people would benefit from option 3, with lower average benefits.) Many who receive only unpaid care would receive new services, and many of the millions receiving at least some formal services would receive more intensive services. A substantial share of the increase in service intensity would come from current Medicaid beneficiaries. Many current-law beneficiaries who receive Medicaid services have service levels below—often far below (Musumeci, Chidambaram, and O’Malley Watts 2019b; Peebles et al. 2017)—the new benefit’s daily limit.⁵²

TABLE 4
Number of LTSS Beneficiaries and Average Benefit under Option 1 in 2020

	Beneficiaries	Total formal services
Total (best guess)	10.0 million	\$40,900
Range	9–11 million	

Sources: Author’s calculations from the Dynamic Simulation of Income Model supplemented with information from the Health and Retirement Study, National Health and Aging Trends Study, National Health Interview Survey, and Medicare Current Beneficiary Survey and published statistics (Eiken 2017; Eiken et al. 2018; Musumeci, Chidambaram, and O’Malley Watts 2019a, 2019b; NAIC 2019; Peebles et al. 2017).

Notes: LTSS = long-term services and supports. A cell is empty when we have chosen to omit estimates because of measurement challenges.

Many people throughout the income distribution would benefit from new services and the family savings generated by the benefit described in option 1. Of the nearly 10 million participants, some would receive cost-sharing relief, some would receive new services, and some would receive both. Table 5 presents some simple projections of the distributional effects for option 1 in 2020, first showing how LTSS costs are distributed under current law. Because people with lower lifetime earnings are much more likely to become disabled, and because disability affects work and savings capacities and can lead to heavy out-of-pocket spending burdens, we see that those in the bottom 20 percent of the income distribution are responsible for over two-fifths (41.5 percent) of total spending. The second column in the table shows how cost-sharing burdens differ across the income distribution. We estimate that the bottom fifth of the income distribution pays for 31.5 percent of families’ current-law out-of-pocket LTSS spending. The differences for out-of-pocket costs are not as steep as those for total spending because Medicaid protects people with lower incomes, albeit with cost sharing.

TABLE 5
Distribution of LTSS Benefits under Current Law and Option 1,
by Income Quintile and Current-Law Spending Burden, 2020

	CURRENT LAW		CHANGES UNDER OPTION 1	
	Total LTSS Spending	Total Family LTSS Spending	New LTSS Spending	Reductions in Family LTSS Spending
	Percent distribution			
Income quintile				
Lowest	41.5	31.5	28.4	18.3
Second	24.1	27.4	24.3	23.4
Middle	17.0	19.3	20.5	23.2
Fourth	11.1	14.3	16.2	23.1
Highest	6.3	7.5	10.2	12.0

Source: Author’s calculations from the Dynamic Simulation of Income Model (run 967).

Notes: LTSS = long-term services and supports. HIPAA = Health Insurance Portability and Accountability Act. Quintiles are defined based on current income. Totals may not sum to 100 because of rounding. Current-law family estimates focus on LTSS for those with severe disabilities.

The new program benefits are progressive, as the program would immediately provide services to people with severe disabilities, many of whom have lower incomes.⁵³ As shown in table 5, about 28 percent of new services—that is, totally new spending that supplements family care—are projected to go to people in the bottom fifth of the income distribution. All people would see reduced out-of-pocket spending, but the middle class receives special relief: each of the second, middle, and fourth income quintiles receives more than 20 percent of the new benefit.

Validation against Prior Analyses of Caregiver Burden and Expanded LTSS Benefits

Because of the challenges associated with estimating new LTSS plans' costs and distributional effects, we compare our projections with estimates from the literature on caregiver burden and projected costs of plans for universal, low-cost HCBS/LTSS without beneficiary cost sharing.

Face validity. To check our projections' face validity, we assume roughly half of families of people with disabilities would continue to rely solely on unpaid family care, some families would use more paid services than they now provide informally, and some would use fewer paid services. If a steady supply of care workers were immediately available, we can crudely approximate that \$200 to \$250 billion in new services could have been required in 2019. Boosting provider payment rates to meet the increased demand could further increase total costs. This simple estimate roughly aligns with our estimate of \$238 billion in new services in 2020.

Prior analyses of proposals. Many prior formal analyses of the costs or distributional effects of universal or near-universal LTSS benefits delivered through proposed social insurance programs have focused on more limited benefits with more stringent eligibility standards than those in some single-payer legislation. Our projections could be validated using three studies that similarly explored using pay-as-you-go financing for broad LTSS benefits.⁵⁴

Our projections for the three options appear broadly consistent with those from other studies after we adjust other studies' projections to be reported in consistent, current-period dollars and account for population size differences in state-specific analyses (i.e., we crudely gross up state analyses to the US population). Our projections are similar to those in Liu and colleagues' 2018 report on single-payer health care legislation in New York state (the New York State Health Act). The report includes sensitivity analyses for an LTSS benefit that would use criteria for functional capacity similar to those in the state's Medicaid program but without the income and asset screens.⁵⁵ Option 1 broadly resembles the intermediate case in Liu and colleagues (2018), and option 3 resembles their high-cost scenario.⁵⁶ Our overall projected cost increases for option 1 are lower than those from Veghte and colleagues' 2019 analysis of a universal home care benefit. However, our cost increases for option 1 are more comparable with those of Veghte and colleagues (2019) when we roughly account for the reduced Medicaid liabilities possibly generated by a new program, assuming it would pay before Medicaid and that families would save on out-of-pocket costs they no longer need to pay.⁵⁷

These projections are higher than our past work, largely because of differences in assumptions, including program generosity.⁵⁸ In our earlier analyses, we made simplifying assumptions that were in keeping with policy discussions at that time but are now too restrictive given the current focus on more expansive benefits.⁵⁹

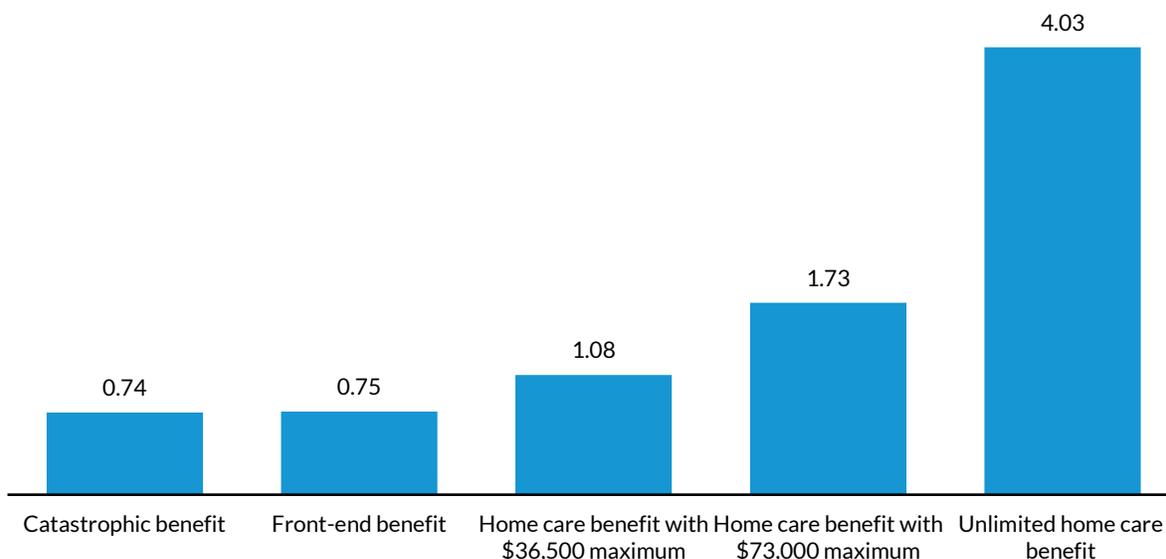
Design Options for More-Limited LTSS Programs

In recent national and state-level debates, policymakers hoping to provide families with relief at a lower cost than would be required for the comprehensive programs discussed here have weighed the trade-offs between various limited, incremental programs. Examples include LTSS programs that cover risk and allow enrollment soon after disability onset (front-end programs), which may include a short waiting period, and programs that start to cover LTSS costs only after a person has been disabled for some time, say two years (back-end, or catastrophic, programs). Some propose weekly hours limits.⁶⁰ Several recent reports provide estimates of the relative costs of different incremental proposals (Armentrout et al. 2017; Veghte et al. 2019).

Figure 5 illustrates how the costs of five different \$100 per day LTSS benefits would vary based on how long the programs would cover benefits, when the programs would take effect, and who the program would cover. (Each program would reimburse services, rather than provide cash benefits, and requires that disabilities meet HIPAA criteria.) The unlimited program (far-right bar) would be less generous than the program we evaluate here because of its daily limit. Actuaries estimate it would require about a 4 percentage-point increase in the Social Security payroll tax rate or its equivalent from an alternative revenue source. Programs that impose benefits limits—whether a dollar or time limit or a waiting period before services are available—and serve a more limited population—future beneficiaries need to have contribute during their working years—could cost less than a fifth as much. Limited programs would also be less risky for governments wary of the possibility that actuarial forecasts might understate costs.

FIGURE 5

Estimated Costs, Shown as Social Security Payroll Tax Rate, for Five More-Limited Options That Expand LTSS Access, 75-Year Rates



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Source: Armentrout and Trapnell (2019), as reported in Veghte and colleagues (2019).

Notes: LTSS = long-term services and supports. The catastrophic benefit is taken from Cohen, Feder, and Favreault (2018). The front-end benefit mirrors that offered in Washington State. The programs would provide \$100/day service benefits and have 90-day elimination periods, except for the catastrophic programs, which would have longer income-related waiting periods. The unlimited home care benefit would take effect immediately and cover the full population.

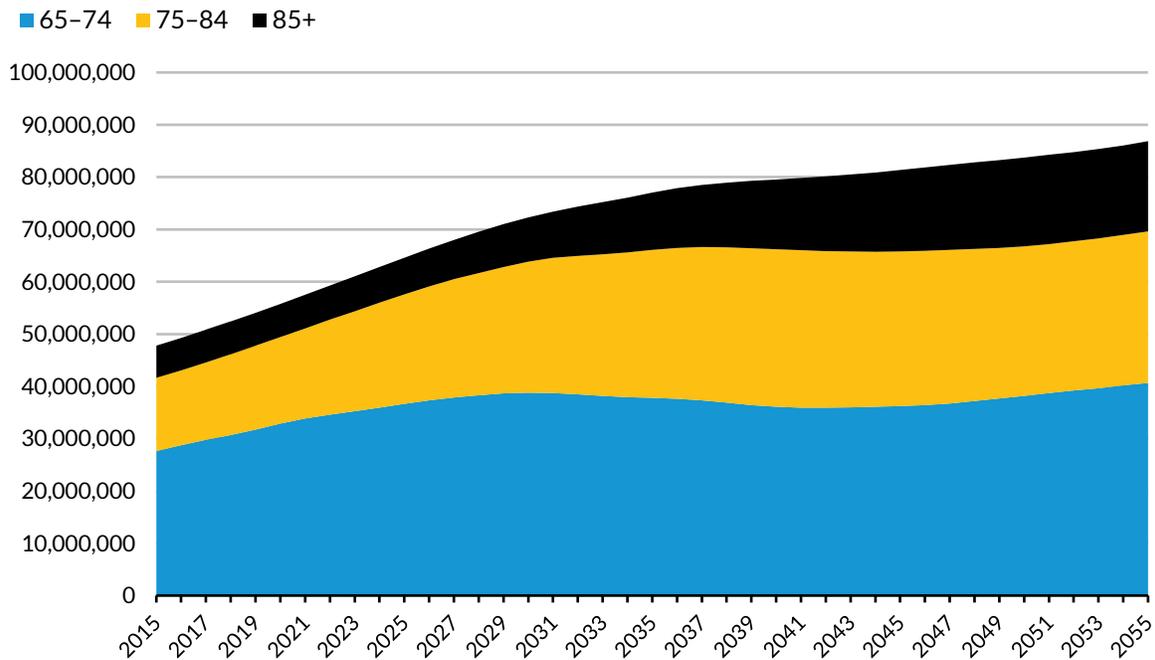
Caveats

Data limitations have hampered analyses of LTSS policy proposals (Favreault and Tumlinson 2019; GAO 2017). Estimates of the number of people with severe disabilities are quite uncertain.⁶¹ Even estimates of the number of people receiving LTSS from Medicaid, and costs for their care, are imprecise. Programs with fewer limits on benefits and no cost sharing are especially challenging to evaluate given the lack of precedent. Our sensitivity analyses underscore just how many assumptions are required and how uncertain these projections are. Other economic, health, and behavioral feedbacks may be relevant and worth integrating into our forecasts. For example, increased HCBS accessibility might reduce the need for health or institutional care.⁶² In that case, it might be appropriate to include feedbacks for health spending in our forecasts. Currently, the literature implies we should not assume large savings (Grabowski 2006; Guo, Konetzka, and Manning 2015; Konetzka 2014; Newcomer et al. 2016). Also, states could respond if the federal government assumes some Medicaid LTSS costs but not others.

Workforce issues will also likely pose challenges for greatly expanding access to care with or without LTSS financing reform. It is difficult to project how the LTSS workforce will evolve and how that will influence demand for services, adding further uncertainty to the projections. Recruiting enough care workers to meet challenges like these could require significant increases in wages and thus provider payment rates. Moreover, LTSS are very personal. Providers often come into care recipients' homes, helping with very personal tasks, like dressing, bathing, and toileting. Relationships between providers and care recipients thus require significant trust, and some people prefer not to have others in their homes.

We have focused on costs and distributional effects in the near term. Outside the 10-year budget window, costs should grow more rapidly, as members of the large baby boomer cohort reach their 80s and 90s, when LTSS needs are greatest. Figure 6, based on Social Security Trustees projections (Board of Trustees 2019), illustrates that the largest growth in the population ages 85 and older will occur after 2029. Also, supply of care workers should further expand, assuming adequate payment rates. Thus, policymakers should carefully consider the chances that future liabilities for expanded LTSS would be higher than our short-range estimates suggest.

FIGURE 6
Growth of the Population Ages 65 and Older, 2015–55
The population ages 85 and older will grow more rapidly after 2029



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Source: Social Security Administration, based on Board of Trustees (2019).

Finally, some proposal developers may not have intended for analysts to interpret their policy specifications literally. Several recent legislative proposals could be interpreted as statements of principle to initiate conversation rather than detailed legislative programs. We hope our and independent analysts' estimates like will spur further discussion and development of LTSS proposals so that actuaries and researchers can do more precise work reflecting proposal developers' intentions. This will enable legislators and voters to weigh the trade-offs between different programs relative to the status quo.

Conclusions

Estimating the costs and distributional effects of broad expansions in LTSS outlined in recent single-payer legislation is difficult given the unprecedented breadth in proposal eligibility and the lack of specificity in proposed benefit packages. Even estimating current-law LTSS expenditures is challenging because of data limitations, as is shown by the literature on potential for underestimating private-pay services and supports because of the “streetlight effect” (Newquist, DeLiema, and Wilber 2015; Seavey and Marquand 2011), state movement to managed LTSS (Eiken et al. 2018, Lewis et al. 2018), and confusion between and confounding of postacute services, home health care, and LTSS. Our projections of LTSS costs and distributional effects under these proposals are highly speculative. However, because of these proposals' policy importance, we still believe developing estimates around them can contribute to the literature, assuming projections are firmly grounded in the best available social science literature, extensive peer review, and appropriate caveats to users.

One important lesson policymakers may take from these analyses is that the level at which they set benefit triggers will significantly affect proposals' reach, and thus their costs. Under current law, eligibility thresholds for public benefits, most notably Medicaid, vary by state, and private benefits vary by plan and company, as do screening and assessment tools (MACPAC 2016, 2017). Generally, only those with the most severe disabilities qualify. Additionally, large amounts of formal and unpaid care—possibly the majority—are now delivered to people with less severe disabilities, suggesting possible large increases in demand if care were free and unlimited or had only high eligibility limits. Limiting or scaling weekly or monthly service amounts or covering only part of LTSS risks will also significantly affect costs and reach.

This study underscores the trade-offs policymakers will likely need to weigh in coming years. If they wish to increase public LTSS financing, they may need to choose between serving different groups of often vulnerable people. Policymakers could markedly reduce LTSS program costs by covering part,

rather than all, of lifetime LTSS risk; limiting daily benefits or service days; grading benefits by disability severity; or requiring future beneficiaries to prefund all or part of their benefits. These choices would not be easy, but of course, maintaining the status quo for LTSS also means that many people will be unserved, underserved, or at risk for large out-of-pocket costs or years of unpaid family caregiving.

Notes

- 1 Other wealthy countries have taken different approaches to financing LTSS, often with universal components (Costa-Font 2019).
- 2 Veterans are eligible for LTSS through the Veterans Administration.
- 3 Community Living Assistance Services and Supports, a voluntary LTSS program that was integrated into the Affordable Care Act, was suspended in 2011 and officially repealed as of January 1, 2013.
- 4 There are important differences in definitions and terminology and within and across plans, and they are often quite nuanced; see Blumberg and Holahan (2019); Liu and Brook (2017); Howard Gleckman, "Medicare for All Has Nothing to Do with Medicare. Call It Something Else," *Forbes*, July 31, 2019, <https://www.forbes.com/sites/howardgleckman/2019/07/31/medicare-for-all-has-nothing-to-do-with-medicare-call-it-something-else/#4252772c6c5c>; and "Compare Medicare-for-All and Public Plan Proposals," Henry J. Kaiser Family Foundation, May 15, 2019, <https://www.kff.org/interactive/compare-medicare-for-all-public-plan-proposals>.
- 5 We adapt some of this text from Medicare's website; see <https://www.medicare.gov/coverage/long-term-care>.
- 6 Measures often account for age, so that assessments for infants and young children account for whether the child's functional capacities allow for a typical, age-appropriate level of independence.
- 7 Section 7702B(c)(2)(B) of the Internal Revenue Code of 1986.
- 8 The ADLs enumerated in the statute are eating, toileting, transferring, bathing, dressing, and continence.
- 9 Residential options cover a broad spectrum, including independent living and assisted living (Freedman and Spillman 2014). Harris-Kojetin and colleagues (2019) use one set of criteria to determine whether to include residential care communities in their sample of LTSS providers and users. These criteria for a residential care community include the following: it must be licensed, registered, listed, certified, or otherwise regulated by the state to provide room and board with at least two meals a day and around-the-clock, on-site supervision; help with personal care, such as bathing and dressing or health-related services, such as medication management; have four or more licensed, certified, or registered beds; have at least one resident currently living in the community; and serve a predominantly adult population.
- 10 See the Centers for Medicare & Medicaid Services website for a description of Medicare home health, available at <https://www.medicare.gov/what-medicare-covers/whats-home-health-care>. Avalere Health (2017, 2018) reports the most frequent diagnoses for those with home health claims; most are decidedly medical, with joint replacement, septicemia, and heart failure being the top three. In tabulations from the Medicare Current Beneficiary Survey, we estimate that less than half of Medicare home health claims are delivered to people estimated to meet HIPAA's definition of having long-term care needs. In prior analyses, we attempted to allocate a portion of Medicare as LTSS (Favreault and Dey 2016), consistent with other authors (Kemper, Komisar, and Alexih 2005).
- 11 Reinhard estimates a value of \$470 billion in 2017 (or \$484 billion after wage indexing this estimate to 2018). The price used to value care is the average of the state minimum wage, median home health aide wage, and median private-pay home health aide wage. This average is lower than the replacement cost if families were to contract with a formal agency.
- 12 For example, Hurd, Martorell, and Langa (2015) estimate the replacement cost for unpaid family care provided to people with dementia ages 71 and older to be about \$255 billion in 2020 under intermediate assumptions (based on Hurd et al. 2013). At ages 71 and older, those with severe cognitive impairment are the majority of people disabled at the HIPAA level. Those with ADL limitations alone comprise another group needing care, suggesting that computations from Spillman and colleagues (2014) are reasonable for a crude approximation.
- 13 These estimates must be interpreted cautiously, as states elect to prioritize different populations through their waiver programs. Data quality surely also varies by state.

- ¹⁴ One can define LTSS in several ways, and different approaches can lead to different conclusions about whether to classify certain expenses as LTSS. Treatment of Medicare-covered services for people with LTSS needs is one challenging issue. Confusion can arise because several prominent government publications, including from the Congressional Research Service and Congressional Budget Office, describe Medicare as one of the primary LTSS payers and describe a significant share of medical services as LTSS (Colello 2018; CBO 2013). Colello (2018), for example, estimates that Medicare pays for about 22 percent of LTSS—split roughly equally between home health agencies and skilled nursing facilities. Hado and Komisar (2019), in contrast, excludes Medicare payments from LTSS spending. See discussion in the next endnote.
- ¹⁵ The Centers for Medicare & Medicaid Services website clearly states, “Medicare doesn’t cover long-term care (also called custodial care), if that’s the only care you need. Most nursing home care is custodial care.” It states further, “You pay 100% for noncovered services, including most long-term care.” For more information, see <https://www.medicare.gov/coverage/long-term-care>.
- ¹⁶ Other calculations in Blumberg and colleagues (2019) address Medicare expenditures for post-acute services. If these LTSS analyses included them, we would risk double counting.
- ¹⁷ The National Association of Insurance Commissioners reports that premium payments for long-term care insurance totaled \$11.64 billion in 2018, lower than the \$12.37 billion in incurred claims.
- ¹⁸ Unlike traditional health insurance coverage, which usually operates on an annual basis, long-term care insurance contracts can cover decades. Policyholders pay premiums, often for many years and for tens of thousands of dollars, for future coverage. If the government instead provided these services at no additional cost, there would likely be pressure to address this inequity. Where government coverage was incomplete, private insurance could help supplement government benefits.
- ¹⁹ Newquist, DeLiema, and Wilber (2015) note the importance of a “streetlight” effect in analyses of home care: Analysts focus too closely on data from government payment records, despite large amounts of care being provided through sources not tracked in these records (Seavey and Marquand 2011). Neglecting these sources could lead analysts to understate use under current law and proposals to change LTSS financing.
- ²⁰ The National Health Expenditure Accounts’ definitions of elements counted are available at <https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/Downloads/quickref.pdf>.
- ²¹ The Veterans Administration’s fiscal year 2020 budget for LTSS was \$9.78 billion (US Department of Veterans Affairs 2019).
- ²² Other sources also provide information on these plans. See, for example, “Compare Medicare-for-All and Public Plan Proposals,” Henry J. Kaiser Family Foundation, May 15, 2019, <https://www.kff.org/interactive/compare-medicare-for-all-public-plan-proposals/>.
- ²³ Washington State’s initiative is the [Long-Term Services and Supports Trust Program](#), H.B. 1087, 66th Leg. Reg. Sess. (Wa. 2019). Representative Frank Pallone’s proposed federal program is Medicare Long-Term Care Services and Supports Act of 2018, H.R. ___, 115th Cong. (Proposed Official Draft 2018). For the discussion draft announcement, see “Pallone Unveils Proposal for Medicare Long-Term Care Benefit,” House Committee on Energy and Commerce, May 2, 2018, <https://energycommerce.house.gov/newsroom/press-releases/pallone-unveils-proposal-for-medicare-long-term-care-benefit>. Armentrout and colleagues (2017) describes some alternative specifications policymakers in Washington state considered when discussing the Long-Term Services and Supports program.
- ²⁴ [Medicare for All Act of 2019](#), H.R. 1384, 116th Cong. (2019).
- ²⁵ [Medicare for America Act of 2019](#), H.R. 2452, 116th Cong. (2019).
- ²⁶ LTSS eligibility could resume seamlessly if functional capacity changes or improves and services are not needed for some time but then functional needs recur. The proposed legislation notes that those in institutional care at

the time of enactment would be informed annually—or upon change in function levels—of options for receiving HCBS, and that they could then choose HCBS over their current care arrangement.

²⁷ [Medicare for All Act of 2019](#), S. 1129, 116th Cong. (2019).

²⁸ In the short run, we assume provider prices would grow by roughly the average of wage and price inflation, varying by payer. Though LTSS are labor intensive, wages have stagnated for many in the low-wage labor market in recent decades.

²⁹ Adopting a uniform national benefit defined by a dollar amount would mean people in different states could potentially obtain different service levels. Genworth (2019) reports that the median hourly price for care from a home health aide was \$30 in the most expensive state (Washington) in 2019. In the least expensive state (Louisiana), it was \$16.88. With a benefit of, say, \$150 per day, a person could purchase about 5 hours per day of care in Hawaii, compared with just over a full business day (8.9 hours) in Louisiana.

³⁰ We assume that service levels for all current-law Medicaid beneficiaries are grandfathered in the new program so that those with more severe disabilities receiving very intensive services—either HCBS or institutional—still receive full reimbursement under the new program. That is, current beneficiaries' Medicaid benefit levels can go up, but they cannot go down.

³¹ See, for example, [American Health Security Act of 2013](#), S. 1782, 113th Cong. (2013) or [Medicare for All Act of 2017](#), S. 1804, 115th Cong. (2017).

³² In 2019, the highest-cost state was Alaska, where median cost for a single night in a semiprivate room was \$994; the lowest-cost states were Oklahoma and Texas, where the median cost was \$160 (Genworth 2019).

³³ Private insurance industry data, for example, are based on a select population: those with the means to purchase insurance and, usually, who are healthy enough to pass underwriting. New policy holders thus exclude those most likely to need LTSS in the near term. People with higher incomes and wealth also have longer life expectancy and lower age-specific morbidity than the general population. Finally, policies require that policyholders' disabilities meet or exceed the policy's standard, which may be stricter than the HIPAA standard.

³⁴ We specifically estimate disability prevalence using data from the Health and Retirement Study, Medicare Current Beneficiary Survey, National Health and Aging Trends Study, and National Health Interview Survey. We anchor our projections at ages 65 and older to the National Health and Aging Trends Study and at ages younger than 65 to the National Health Interview Survey. We compare prevalence of HIPAA-level disability with prevalence of disability that meets a less restrictive standard.

³⁵ Focusing only on the types of services the National Health Expenditure Accounts captures could lead to understating LTSS spending, because those data may exclude significant amounts of paid home care. Doty (2017) notes that the private-pay home care sector is rapidly evolving. In its survey of home care providers, Home Care Pulse estimates that for a sample of home care firms, about 72 percent of care was paid privately and an additional 11 percent was paid by long-term care insurance. Though the Home Care Pulse survey sample is not representative, it underscores how some government statistics may miss an important LTSS sector that needs to be considered when estimating costs for expansive, subsidized LTSS. Earlier estimates from the 2004 National Long-Term Care Survey also highlight the importance of private pay for LTSS in the community (Houser, Gibson, and Redfoot 2010).

³⁶ We expect that nursing home care use would increase more modestly, and most new beneficiaries would receive HCBS.

³⁷ Experience from the Balanced Budget Act of 1997 could provide insight into possible behavioral change in the US (Komisar 2002; McCall et al. 2001; Murtaugh et al. 2003). That legislation—enacted partly in response to growing Medicare home health claims, some of which were believed to be largely LTSS and thus outside Medicare's scope—markedly changed provider incentives for providing care. After enactment, claims fell precipitously and became more concentrated on apparent postacute services (Komisar 2002).

- ³⁸ Almost all the plans in table 1 have zero cost sharing at the point of service. Under current law, Medicaid beneficiaries must pay significant cost shares. In the case of nursing home care, beneficiaries must turn over almost all of their income, except for a small personal needs allowance (which varies by state and, in some cases, can be as low as \$30 per month and is typically not indexed for inflation). Johnson and Lindner (2016) estimate that many older low- and moderate-income adults need to spend more to stay in the community than would be permitted with Medicaid income allowances for HCBS beneficiaries. Unmarried people are especially likely to have expenses that exceed the Medicaid income allowances.
- ³⁹ For programs with a 20 percent copayment, Broyles and colleagues (2010) assume a two-fold increase in participation, from 15 percent to 30 percent. Among people already receiving services in the community, they assume an increase in services, from 10 to 15 hours per week.
- ⁴⁰ In prior work, our colleagues have also addressed this question about intensity of LTSS use. In analyses based on the National Long-Term Care Survey, Spillman (2016) found that those with less severe disabilities use both formal and unpaid family care less intensively than their more severely disabled counterparts. These analyses relied on data in which survey responses were matched to payment records, bolstering the quality of measurement.
- ⁴¹ This assumption is consistent with earlier actuarial analyses of a similar benefit (Armentrout and Trapnell 2019).
- ⁴² Within all three sensitivity tests, we assume that those with lower disability levels use fewer services (i.e., supplement unpaid family care at a lower rate) than those with higher disability levels.
- ⁴³ Because home care work is less specialized and requires relatively little formal training, provider shortages in this area could be met more easily than shortages in other areas (e.g., medical specialties which require years of training and special certifications), assuming wages were increased enough.
- ⁴⁴ Other factors, like future morbidity levels, will also drive future LTSS costs. If age-specific levels of cognitive impairment change, projected costs for LTSS will change as well. However, because we only consider the near term and morbidity and mortality changes tend to be modest over shorter time horizons, our sensitivity analyses focus on other uncertainties.
- ⁴⁵ Estimates of disability prevalence differ depending on question wording and sampling strategies (Freedman et al. 2013). The definition in HIPAA requires one to “need substantial assistance” with at least two of six specified ADLs that are expected to last at least 90 days. To get at different concepts, many surveys ask related questions, like whether a person has “difficulty with, needs help with, or receives help with” performing an ADL. The difficulty threshold is less stringent than the help or assistance thresholds. Receipt of help is not equivalent to a need for help; indeed, it may be associated with presence of a caregiver. Some who need help may not receive it, and some may report that they do not do an activity either because they no longer do it or because they never did it. (For example, one may report not managing family finances or doing light housework because a spouse takes care of it, not because one is too impaired to perform the activity without help.)
- ⁴⁶ The model relies on high-quality longitudinal, nationally representative data from a range of surveys, including the Health and Retirement Study, National Health and Aging Trends Study, and the Medicare Current Beneficiary Survey. First, it estimates the prevalence of LTSS needs, identifying whether each person ages 51 and older has IADL or ADL limitations. It also projects cognitive status for those ages 65 and older. Then it projects prevalence and intensity of service use, considering nights at a nursing home, hours of formal (paid) home care, and nights of residential care (sometimes termed assisted living or continuing care). Next, it projects payments for care, separately examining Medicaid, Medicare, private long-term care insurance, other public programs (e.g., from the Veterans Administration), and families’ out-of-pocket spending. The model disentangles postacute stays in nursing facilities, which Medicare generally covers, from custodial care, which Medicare does not cover. We exclude such stays in estimates of LTSS needs except when a person with HIPAA-level needs otherwise would have been using LTSS. We rigorously compare DYNASIM’s aggregate current-law LTSS payments with estimates from other sources, including Medicaid LTSS estimates from Eiken (2017) and Eiken and colleagues (2018) and private long-term care insurance estimates from NAIC (2018). When we lack reliable aggregate data with which to compare our projections, we use residual methods. In past work, we calibrated

DYNASIM cost projections for programs providing benefits at the HIPAA disability level so they were comparable with those from two firms' actuarial models. For more detail on DYNASIM's LTSS capacities, see the appendix to Favreault, Gleckman, and Johnson (2015). Favreault, Smith, and Johnson (2015) provide an overview of the larger model.

- ⁴⁷ Wage indexing these values to 2020 to account solely for inflation, estimated LTSS expenditures would be \$424 billion including Medicare and \$332 billion excluding Medicare. The wage-indexed value for Medicaid for 2020 is \$179 billion.
- ⁴⁸ Wage indexing Hado and Komisar (2019)'s estimate to 2020 to account solely for inflation, estimated LTSS expenditures would be \$263 billion, including an estimated \$150 billion in Medicaid costs.
- ⁴⁹ Our Medicaid estimate is higher than those of Colello (2018) or Hado and Komisar (2019) but more closely tracks that of Eiken and colleagues (2018), who report Medicaid LTSS spending of \$167 billion in federal fiscal year 2016. Wage indexing this to 2020 yields adjusted LTSS spending of \$194.1 billion, assuming no changes other than inflation. Our estimates of the composition of spending differ from some of our prior reports, which focused on people ages 65 and older. Differences arise because people with disabilities younger than age 65 are far more reliant on Medicaid than older adults, and because some of those prior analyses included assisted living. CRS estimates for 2018 (Colello 2020) were released after our main report (Blumberg, Holahan, Buettgens et al. 2019) and thus were not integrated into our baseline. These revised estimates suggest faster than inflation growth in LTSS from 2016 to 2018 in both overall LTSS spending and Medicaid LTSS.
- ⁵⁰ Because we have used conservative assumptions about benefit take-up in the intermediate estimate, the difference between the low-cost and intermediate estimates is larger than the difference between the high-cost and intermediate estimates.
- ⁵¹ For more on the relationship between Medicaid and Medicare in many recent health care proposals, see "Medicare-for-All Would Eliminate Most or All of Medicaid, but No One Is Talking about It," Henry J. Kaiser Family Foundation, *Perspectives* (blog), July 18, 2019, <https://www.kff.org/health-reform/perspective/medicaid-should-be-a-bigger-part-of-the-medicare-for-all-debate/>.
- ⁵² Feder and Komisar (2012) also detail some of the differences in Medicaid LTSS across states.
- ⁵³ Some LTSS proposals would require people to contribute in advance to their LTSS coverage (e.g., by requiring 10 or more years of contributions to qualify). Screening based on work history will have important effects on people with early-onset disabilities, who may not qualify with strict requirements.
- ⁵⁴ That is, each year the government would pay for all benefits through premiums and taxes, and people would not have to prepay a significant share of their own benefits. Under such approaches, policymakers could periodically adjust revenues so the program's inflows would meet demand for program services. Under advance-funded proposals, policymakers aim to have each generation (cohort) fully or nearly fully pay for its own benefits through some mix of earlier-career prefunding and premiums in later life. Systems with advance-funded LTSS benefits could charge lower rates because contributions exceed benefits for many initial years, and the reserves could accrue interest. For a discussion of alternative financing approaches, see Veghte and colleagues (2019). Lepore (2019) also presents a history of LTSS financing discussions.
- ⁵⁵ Because legislators excluded LTSS benefits from the bill's initial benefits package but charged program trustees to develop a plan for adding them later, Liu and colleagues (2018) exclude LTSS benefits from their main analyses of the proposal but discuss them in sensitivity analyses. Liu and colleagues (2018) also assume that the new program would pay for all formal LTSS that families pay for out of pocket under the status quo, and that caregiver burdens would decline as strapped families would supplement about 50 percent of current informal care hours with formal care paid for by the new program. Liu and colleagues (2018) assume that 90 percent of this paid-care increase would be delivered in the home, and 10 percent would shift to nursing homes. Two additional sensitivity analyses consider alternative substitution of unpaid family care with paid care—assuming more (75 percent with a 300 percent increase in home care and 15 percent increase in nursing care) and less (25

percent and thus a 100 percent increase in home care and 5 percent increase in nursing care) care—to bracket the main LTSS sensitivity analysis.

- ⁵⁶ Drawing from Health and Retirement Study/Asset and Health Dynamics among the Oldest Old–based estimates of current spending levels on formal care and the value of unpaid care for the older population in Hurd and colleagues (2013), Liu and colleagues (2018) estimate home care increases of close to 200 percent (i.e., use would triple) and institutional service increases of 10 percent. This yields total estimated costs of \$17.8 billion in 2022, \$19.4 billion in 2026, and \$21.5 billion in 2031. Naïvely grossing these up to national population totals yields roughly \$292 billion in 2022. However, this study, focused on New York state, cannot be generalized to the entire US population; New York is a wealthy, high-income state with a healthy, long-lived population (US Burden of Disease Collaborators 2018) and more generous current-law LTSS coverage than most other states, both in prevalence of benefit receipt and intensity of services among recipients (Gonçalves, Weaver, and Konetzka 2018). The overall share of the aged population that receives paid LTSS (Medicaid and non-Medicaid) is much higher—and thus the level of unmet LTSS need is almost certainly lower—in New York than in many other states. However, provider costs are higher in New York than in many other states (Genworth 2019; Hansen Hunter 2018). On net, then, the higher costs per unit may partially offset the lower prevalence of unmet LTSS need, making it difficult to know how to adjust these estimates for New York to represent the US as a whole.
- ⁵⁷ Veghte and colleagues (2019) recently reported actuarial estimates of costs (from Armentrout and Trapnell 2019) for a range of LTSS benefits as part of a universal family care program. It reports that an unlimited service reimbursement home health benefit of up to \$100 per day with eligibility criteria set at HIPAA levels and pay-as-you-go financing that is solvent for 75 years would require a Social Security tax rate of just over 4 percent. (They also provide estimates using three alternative financing bases: the federal income tax base, the Medicare payroll tax base plus the additional Medicare tax, and this second base plus the net investment income tax.) This tax rate would have netted about \$306 billion in revenue in 2019; mechanically grossing this up to fund a benefit of \$150 per day (assuming no one would take a partial benefit) could have led to 2019 costs as high as \$450 billion in 2019. This estimate does not consider potential Medicaid cost offsets or other program interactions (e.g., with Veterans Administration care). One can surmise that Medicaid HCBS costs not exceeding the benefit ceiling would be paid first by the new program unless legislation required otherwise. Subtracting potential Medicaid offsets could reduce total costs by about \$60 billion. In generating these projections, Armentrout and Trapnell (2019) assumed disability incidence of 110 percent of current incidence, that beneficiaries would use services for six days per week, and administrative costs of 7 percent.
- ⁵⁸ Our prior work evaluating Senator Sanders’s 2016 campaign statements about health care found that including an LTSS benefit within a single-payer proposal could have added \$68.4 billion in new services in 2017, and that transfer of existing out-of-pocket payments to the new program would amount to an additional \$62.5 billion (Holahan et al. 2016). Shifting such a program’s costs from Medicaid and households and broadening available benefits would have increased estimated federal spending on LTSS by \$212.1 billion in 2017. (States would have saved \$73 billion as the federal government took over responsibility for those formerly receiving Medicaid.) Because the Sanders campaign’s website did not fully specify the LTSS benefit package or eligibility levels, we assumed more restrictive access than more recent single-payer proposals specify. See the next endnote.
- ⁵⁹ Our intermediate estimates for the base program are higher than our prior estimates (Holahan et al. 2016), even though option 1, consistent with the most recent legislation Sanders introduced, would maintain Medicaid’s institutional component of LTSS. This would preserve state contributions for institutional LTSS and limit growth in federal burdens relative to plans that would cover both institutional care and HCBS. Besides anticipated inflation and population growth between 2017 and 2020, which would lead to expected increases of about 12 percent (for inflation) and 2 percent (for population growth), five other factors drive the increase. First is a higher maximum home care benefit level, now \$150 per day. Second, we assume fully phased-in benefits in 2020; our prior analyses assumed that supply constraints (too few home care workers) and families’ unfamiliarity with the program would limit utilization in the first several years of the program, especially the first year. Third, our earlier analyses assumed home care benefits would be limited to five days per week of service, compared with up to seven days per week for people with high needs in this analysis; the prior analyses also

assumed limits on hours of care per day based on utilization patterns with price constraints. Fourth, our prior analyses assumed that the program's eligibility apparatus would be strict, and few people with disabilities not meeting the HIPAA criteria would receive benefits. In these analyses, we assume some disability "inflation," consistent with recent actuarial studies' assumptions and the limited detail on disability triggers in single-payer proposals. Finally, our earlier study assumed a brief waiting period for benefits, consistent with proposals at that time; this study does not include one. If any of these factors were to change, then cost estimates would change. Our sensitivity analyses suggest some potential bounds.

⁶⁰ Karen Davis, Amber Willink, and Cathy Schoen, "Medicare Help at Home," *Health Affairs Blog*, April 13, 2016, <https://www.healthaffairs.org/doi/10.1377/hblog20160413.054429/full/>.

⁶¹ Brookmeyer and colleagues (2018), for example, provides confidence intervals for estimates of the number of people with Alzheimer's disease and other dementias. Their best-guess estimates are that in 2017, 3.65 million people ages 30 and older in the US had clinical Alzheimer's disease, with a range from 1.7 and 7.62 million, and 6.08 million people were living with moderate cognitive impairment, with a range of 3.11 to 11.64 million. These ranges illustrate the variation in good-faith estimates and the difficulty of accurately forecasting disability needs.

⁶² This could occur, for example, because of better medication management, fewer falls, and other improvements to beneficiaries' lives.

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