



## Health Benefits for Serious Illness Care: Current State and Opportunities for Improvement

To date, the movement toward value-based care in the U.S. has primarily focused on quality measurement and payment reform. Changes in health benefit designs that increase member cost sharing are also occurring as payers and purchasers look for ways to achieve greater value in health care spending. While payment reform focuses on incentivizing providers to provide higher quality, patient-centered services at lower cost, benefit designs typically have not provided complementary incentives to influence member behavior and encourage them to use higher value providers and services. However, when aligned, payment reform and benefit design can work in tandem to incentivize members to use high-value health care services and thereby reward high-value health care providers.

Benefit designs with high member cost sharing have inherent tradeoffs between reducing costs and maintaining or increasing member access. This raises concerns for individuals with serious illness, which can be defined as one or more conditions serious enough that general health and function decline and lead to the end of life. Individuals with serious illness have complex needs that require significant care planning, ongoing care coordination, and utilization of a wide range of services. In addition to acute care needs related to their condition, the seriously ill may need home health services to manage symptoms, social care to address non-medical needs, and palliative care and hospice as their condition worsens. Research indicates that home- and community-based services are preferred by individuals with serious illness and are less expensive than inpatient or long-term residential care. Home- and community-based services can also help alleviate financial and emotional burdens for the seriously ill and their caregivers.

Properly designed, benefits for seriously ill individuals and their caregivers can support access to high quality, affordable, community-based care that is respectful of patient preferences and needs. However, when benefit designs are poorly constructed, the seriously ill may face significant financial barriers and coverage that favors institutional care over community-based services, regardless of patient preference. In both cases, benefit design choices also significantly impact spending by purchasers and payers.

In this paper, we assess the current landscape of health benefits for serious illness care, with a focus on medical services, community-based long-term services and supports, and caregiving benefits. Based on the findings of our assessment, we identify stakeholders that are advantaged and disadvantaged by the current system and provide recommendations for benefits-related policy changes and other actions that will promote expanded access to community-based serious illness care. We also highlight case examples of innovative approaches to health benefits for the seriously ill.

## Conceptual Approach and Methods

Three elements of health benefit structures impact access to services, including serious illness care services: (1) **what services** are covered, (2) **how cost sharing** is designed and distributed, and (3) **who** is part of the **provider network**. Within each of these elements, there is a tradeoff between increased access to services and lower spending.

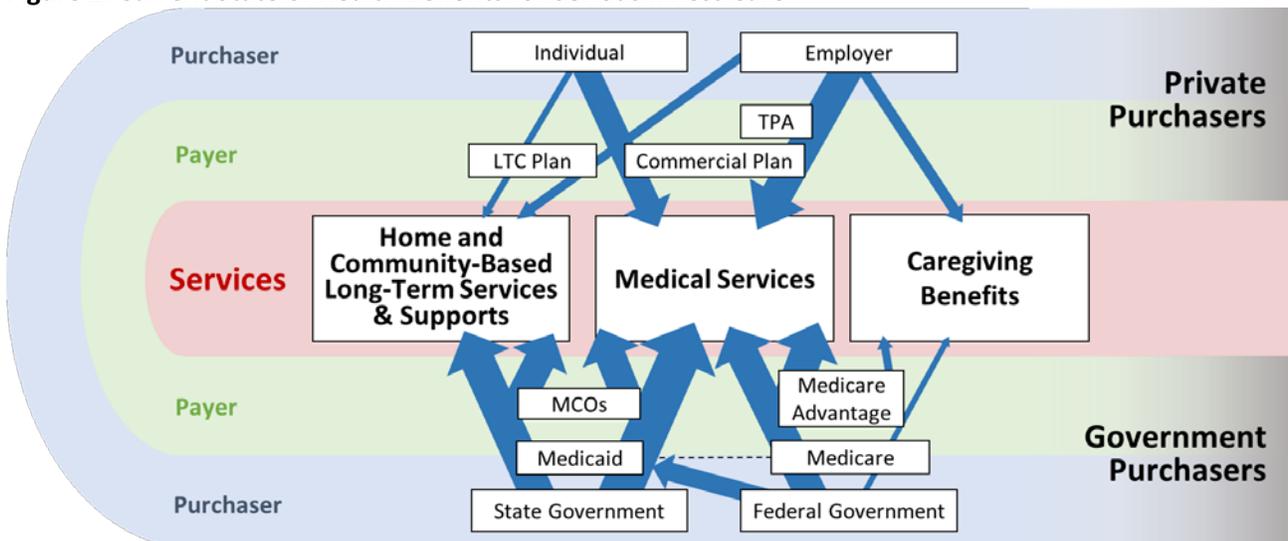
To better understand the health benefits landscape for serious illness care, we assessed the current state and trends for the three elements. The assessment was conducted through internet-based research and semi-structured interviews with key informants. The findings of the assessment are organized around the three elements of health benefits structure.

## The Current State of Serious Illness Care Benefits

Figure 1 provides an illustration of the current provision of health benefits for serious illness care in the U.S. Benefits for serious illness care have been placed into three categories: medical services, home- and community-based long-term services and supports, and caregiving benefits. The figure identifies the purchasers and payers for these benefits. In addition, it distinguishes between private insurance, which includes individual and employer-based health plans, and government programs, which includes Medicare and Medicaid.

Further, the relative size of the arrows signifies the level of access individuals with serious illness have to these benefits as a result of services covered, cost-sharing, and provider network design. For example, employer-based insurance plans tend to have less cost-sharing and more extensive provider networks than individual plans, typically resulting in better access to medical services, so the arrow from “Employer” to “Medical Services” is larger than the arrow from “Individual” to “Medical Services.” However, neither provides significant coverage of home and community-based long-term services and supports, so the arrows to those services are smaller.

**Figure 1. Current State of Health Benefits for Serious Illness Care**





In the following sections, we present the findings from our assessment of covered services, cost-sharing, and provider network design. For each element, we consider the current state and how use of the element by private purchasers and government programs facilitates or limits access to serious illness care. We also highlight trends and notable recent developments.

## Covered Services

### *Medical Services*

Due to the complexity of their conditions, the availability of comprehensive medical services is critical to ensuring that individuals with serious illness have access to needed services. These needed services include inpatient and outpatient hospital services, physician services, post-acute care, palliative care, hospice, and prescription drugs. Care coordination and advanced care planning help promote patient-centered care.

*Private Insurance.* About half of all Americans receive health insurance through employers.<sup>2</sup> Employer-based insurance typically covers a comprehensive set of medical services, including the types of services most needed by the seriously ill. Employer-based insurance has historically covered more services than the individual market. However, since implementation of the Affordable Care Act, plans in the individual market – both on the Health Insurance Exchanges and not – must cover 10 groups of essential health benefits (EHBs), which include ambulatory care, prescription drugs, preventive services, chronic disease management, and other services. Hospice is not included in the EHBs, and as of 2015, only the 11 states and the District of Columbia explicitly require that hospice services be covered by Exchange plans.<sup>3</sup> Box 1 lists the EHBs.

While both the employer and individual markets typically cover a wide range of services, access may be limited through prior authorization requirements and limitations on length of stay. For example, a recent survey of California hospices found that hospice services for privately-insured patients are often delayed due to authorization requirements. The study also found that about half of the private plans reviewed have restrictions on length of stay in hospice, ranging from 100 days to 12 months.<sup>4</sup>

Community-based palliative care services are often delivered in the home by teams of providers, including nurses and social workers. These services are different than home health services, which are typically time limited and for treatment of a specific condition. Private plans are increasingly covering provision of these services in the home setting, but the services typically must be deemed medically necessary and require pre-authorization. In addition, insurers typically do not reimburse providers for travel time or mileage, making it less financially feasible for providers.

#### *Box 1. 10 Essential Health Benefits<sup>1</sup>*

- Ambulatory patient services (outpatient services)
- Emergency services
- Hospitalization
- Maternity and newborn care
- Mental health and substance use disorder services, including behavioral health treatment
- Prescription drugs
- Rehabilitative and habilitative services (those that help patients acquire, maintain, or improve skills necessary for daily functioning) and devices
- Laboratory services
- Preventive and wellness services and chronic disease management
- Pediatric services, including oral and vision care



Telehealth services have many of the same benefits as home visits, allowing seriously ill patients to receive services without having to travel to a clinic or hospital. Private coverage of telehealth services is becoming more common in private plans, largely driven by state coverage mandates. As shown in Figure 2, 32 states and the District of Columbia have some form of mandate for private coverage of telehealth services.<sup>5</sup>

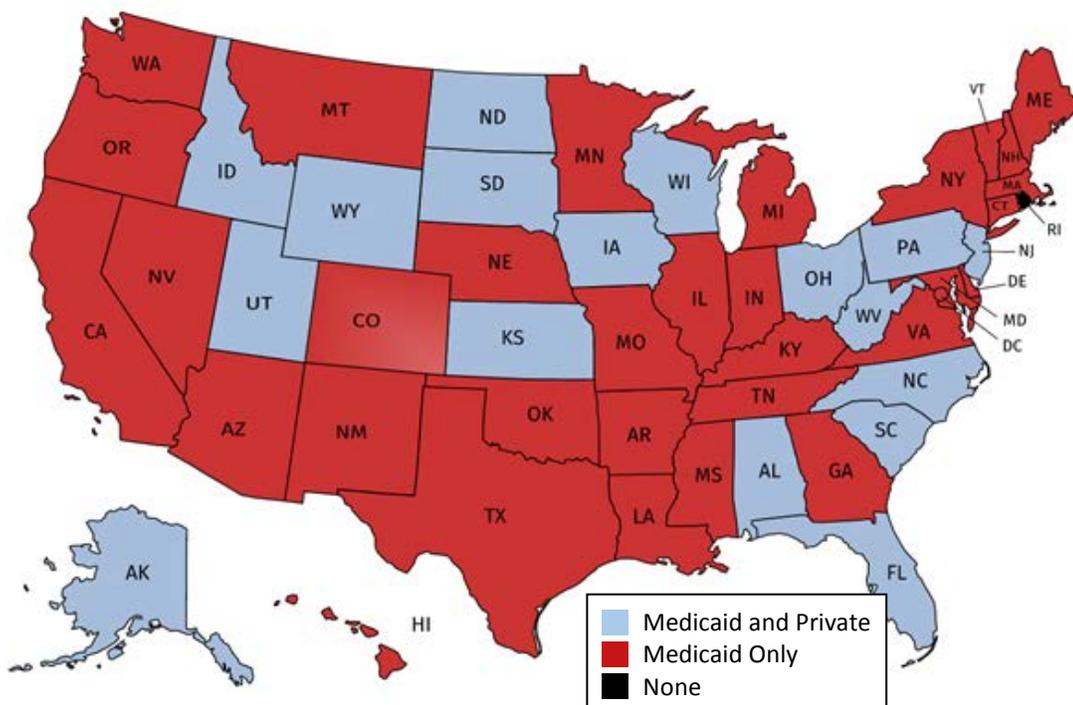
*Medicare and Medicaid.* By law, Medicare provides comprehensive coverage for medical services deemed “medically necessary.” Part A includes inpatient care, skilled nursing, lab tests, hospice (for patients with a prognosis of 6 months or less), home health, and other acute care-related services. Part B includes physician services, behavioral health, and certain preventive services, among others.

Recently, Medicare began covering Chronic Care Management (CCM) services for the first time. CCM includes advanced care planning, care coordination, patient assessments, and other services of relevance to the seriously ill. CCM services provided after the initial visit may be performed telephonically.<sup>6</sup> While CCM provides reimbursement for needed services, uptake has been low due to patient consent and copayment requirements.<sup>7</sup> Outside of CCM, Medicare makes no distinction regarding where services are delivered, meaning that a nurse or social worker can provide services in a patient’s home and still receive the same level reimbursement. However, as in private plans, there is typically no allowance for travel time or mileage.<sup>8</sup> Medicare also covers some telehealth services, including office visits conducted by videoconference. However, there are significant restrictions. The beneficiary must be receiving the service in a rural location, and the beneficiary’s home is not considered a qualifying site.<sup>9</sup>

Medicare Advantage (MA) plans are allowed to cover more services than are covered by fee-for-service Medicare, and they often do. Many MA plans offer special programs for the seriously ill, in which the plan provides or covers supplemental services such as advance care planning and in-home visits by nurses and social workers. MA plans are required to provide telehealth services as part of the Part B benefit, and many MA plans provide additional supplemental telehealth services, indicating that they see these services as having a return on investment.<sup>10</sup> Box 6 provides a description of how these types of supplemental MA services are being deployed in practice by UPMC Health Plans.

The scope of Medicaid covered medical services varies by state. All states are required to provide a set of mandatory benefits, including inpatient and outpatient services, screenings, physician services, home health services, and laboratory services. Hospice and telehealth services are optional, and the most recent available survey found that 41 states cover hospice services for adults.<sup>11</sup> In states that do not cover hospice, these services may still be available through Medicaid managed care plans. As shown in Figure 2, all but one state (Rhode Island) provides some level of Medicaid telehealth coverage.

Figure 2. State Medicaid Coverage and Private Payer Mandates for Telehealth Services (2016)<sup>12</sup>



### **Home- and Community-Based Long-Term Services and Supports (HCBS)**

Long-term services and supports in home- and community-based settings are non-medical services such as home care, social care, household activities, and transportation. These services address activities of daily living (ADLs) such as eating, toileting, bathing, and dressing, as well as instrumental activities of daily living (IADLs) such as meal preparation and housekeeping. They are distinct from home health services, which are medical services provided in the home setting. These services are critical for the seriously ill, who have functional limitations that prevent them from attending to their ADLs and IADLs without assistance. See Box 2 for definitions of terms related to these services and plans that provide them.

#### **Box 2. Definitions of Terms Related to Non-Medical Services and Related Plans<sup>13</sup>**

- **Long-Term Services and Supports** are a broad range of paid and unpaid medical and personal care services that individuals may need on an ongoing basis for assistance with ADLs and IADLs. These services may be provided in either institutional or home and community settings.
- **Home and Community-Based Services** are LTSS services provided in the home or in community settings such as adult day care centers. Compared to institutional LTSS, HCBS are more focused on personal care services and less on medical services.
- **Long-Term Care Insurance Plans** are private insurance plans that typically cover LTSS in both institutional and home- and community-based settings.



*Private insurance.* Employer and individual health insurance plans very rarely cover HCBS. Long-term care (LTC) insurance, which does cover HCBS in some cases, may be offered through employers and may be purchased by individuals. However, only About 11 percent of individuals age 65 and older have LTC insurance.<sup>14</sup> LTC insurance is more expensive for individuals who are diagnosed with a chronic condition, so it is advantageous to purchase LTC insurance before it is needed. LTC insurance companies can also deny coverage due to pre-existing conditions. The coverage provided can also be limited to a small number of services.<sup>15</sup> Due to the limited uptake of LTC insurance, and that coverage may be limited even when individuals have a policy, self-pay is the largest source of payment for HCBS outside of Medicaid.

*Medicare and Medicaid.* Medicaid is the primary payer of HCBS, mostly through 1915(c) waivers from CMS.<sup>16</sup> Medicaid HCBS services are wide-ranging, from home-based skilled nursing care and physical therapy to transportation and meal delivery. HCBS accounts for more than half of all Medicaid spending on LTC nationwide, although there is variation in the types of waivers and services offered by states. Moreover, while all states provide HCBS, some states restrict access through financial eligibility standards and enrollment limits.<sup>17</sup>

The financial eligibility standards for HCBS are often more restrictive than those for general Medicaid eligibility. Due to financial requirements, many individuals “spend down” their assets to qualify for Medicaid and receive coverage for long-term care, including HCBS in states that provide these services.<sup>18</sup> Due to lower costs compared to institutional care, state Medicaid programs often encourage use of HCBS, though in some states, Medicaid HCBS are provided through managed care organizations (MCOs) to help limit spending. There is a common misconception that Medicare covers HCBS, which it does not except for some special populations. However, MA Special Needs Plans (SNPs) for individuals who are dually eligible for Medicare and Medicaid do provide coverage of HCBS in states with managed HCBS.<sup>19</sup>

Federal funding for Medicaid has been uncertain recently. Various bills introduced in the Senate and House of Representatives in 2017 would repeal the ACA Medicaid expansion and establish block grants or per-capita caps for federal funding that would result in funding reductions over time.<sup>20</sup> Such changes in Medicaid financing would put HCBS at risk, as states would likely choose to cut HCBS before cutting medical services.

Outside of Medicaid coverage, many HCBS are provided directly by the federal, state, and local governments. Examples include Meals on Wheels and other nutrition programs, transportation programs, and housing assistance. These programs are often provided or coordinated by Area Agencies on Aging. However, these services are often not integrated with medical services and coordinated with other HCBS services, and patients and their caregivers are often unaware of their availability.<sup>21</sup>

### **Caregiving Benefits**

Most seriously ill individuals rely on informal caregiving from family and friends, in part due to the expense of formal caregiving. This puts a heavy burden on informal caregivers, which are disproportionately older women.<sup>22</sup> The most comprehensive benefit for caregiving is unpaid or paid family and medical leave, in which employees are permitted time off to care for a family member. Beyond paid time off, health plans and long-term care insurance plans may offer limited training and resources for caregivers and limited respite care benefits.

*Employer benefits and private insurance.* Since 1993, most employees have had access to unpaid leave for caregiving because of the Family and Medical Leave Act (FMLA). The law explicitly defines and makes the leave



available for caregiving to the seriously ill. However, only about 14 percent of employees in the U.S. have access to paid family and medical leave. While there is no national benefit, three states (California, New Jersey, and Rhode Island) have paid family and medical leave laws. New York, the District of Columbia, and Washington state have enacted laws, but they have not yet taken effect (see Box 3). The benefit ranges from four to six weeks paid leave for family care. In addition, about 65 percent of employees in the U.S. have paid sick leave, which in some cases may be used for caregiving.<sup>23</sup>

**Box 3. State Paid Family and Medical Leave Laws<sup>24</sup>**

	California	New Jersey	Rhode Island	New York	District of Columbia	Washington
<b>Enacted and Implemented</b>	Enacted 2002 Effective 2004	Enacted 2008 Effective 2009	Enacted 2013 Effective 2014	Enacted 2016 Effective 2018	Enacted 2017 Effective 2020	Enacted 2017 Effective 2020
<b>Reasons for Leave</b>	Caregiving for new child or family member, or care for own disability	Caregiving for new child or family member, or care for own disability	Caregiving for new child or family member, or care for own disability	Caregiving for new child or family member, or care for own disability	Caregiving for new child or family member, or care for own disability	Caregiving for new child or family member, or care for own disability
<b>Length of Benefit</b>	Six weeks for family, 52 weeks for own disability	Six weeks for family, 26 weeks for own disability	Four weeks for family, 30 weeks for own disability	Eight weeks for family and 26 weeks for own disability	Eight weeks parental, six for family, and two for own disability	Twelve weeks for either family or child leave, sixteen weeks for a combination
<b>Employers Covered</b>	All private sector, only some public employees covered	Private and public employees	All private sector employees covered, some public covered	Most private sector employers, certain public employers can opt-in	Private sector employers, excludes government employees	Private and public employees
<b>Benefit Amount</b>	55% of average weekly wage (AWW), max of \$1,173 per week	66% of AWW, max of \$633 per week	Average weekly benefit is 4.62% of wages paid in highest quarter of base period, max of \$817 per week	50% state AWW for family care, 5% for own disability, max of \$170 per week	90% of AWW up to 150% of minimum wage, 50% after 150% of minimum wage, max of \$1,000 per week	90% of AWW or up to \$1,000 per week

While still very rare, employer paid leave benefits for caregiving are becoming more common. In a recent survey by AARP and the Northeast Business Group on Health, half of human resources managers reported that their company leadership will support more friendly caregiving policies in the future.<sup>25</sup> A few national companies have begun offering paid caregiving leave. For instance, Deloitte recently began offering up to 16 weeks of paid time off for caregiving. See Box 4 for a description of Deloitte’s program. Other examples of employers offering similar policies include AARP and several technology companies, likely because of the California law.

There is very rarely any caregiving benefit provided in health plans available in the individual market. However, many LTC insurance plans offer limited respite care and caregiver training and resources.<sup>26</sup> Plans offering these services tend to have more comprehensive benefit packages overall, resulting in higher premiums compared to



more limited LTC plans. The high cost further limits the accessibility of caregiver services, even among those able to afford LTC insurance.

*Medicare and Medicaid.* The only caregiving-related benefit provided in fee-for-service Medicare is respite care when a family member qualifies for hospice services. To receive the benefit, the patient must be eligible for hospice. The patient is admitted to an inpatient hospital or skilled nursing facility setting to receive hospice services, permitting the caregiver to have respite at home. The benefit is limited to five days. In addition, some MA plans – especially SNPs – offer limited respite care, as well as training resources for caregivers. Similarly, the only caregiving-related benefit provided in Medicaid is respite care. These services are offered in states with various waiver programs for long-term care, including the HCBS waiver.<sup>27,28</sup>

#### *Box 4: Case Example – Deloitte Caregiving Benefit*

Deloitte’s Family Leave Program provides up to 16 weeks of paid time off for eldercare, spousal care, and childcare for all employees. The policy states that employees must take at least 3 consecutive days off when utilizing the benefit, as it is meant for serious issues, but the 16 weeks of paid leave can be spread throughout the entire year. There is an approval process for accessing the benefit, which requires documentation from a health care provider regarding the situation.

Deloitte recognizes that they have a multigenerational workforce, and offering flexible time off for caregiving provides for a more productive workforce with greater longevity with the company. The program was designed to assist individuals not with 24/7 caregiving, but to handle issues that may arise with a family member or loved one.

Cathy Engelbert, Chief Executive Officer of Deloitte, stated in a press release from the company that, “By adding support for eldercare, spousal care, and children beyond the birth stage, Deloitte’s family leave program provides our people with the time they need to focus on their families in important times of need.”

## **Cost Sharing**

Beneficiary cost sharing, through deductibles, copayments, and coinsurance (see Box 5), has a significant impact on utilization of services. Use of cost-sharing is one of the common ways that health plans limit utilization across both government programs and private health plans. In recent years, high-deductible health plans have become increasingly common, raising questions about the impact on patient access to needed services. While there is a clear tradeoff between cost-sharing and access, value-based insurance designs (VBIDs) are an approach that limits cost sharing for high-value services, helping ensure access while keeping spending low.

#### *Box 5. Definitions of Cost-Sharing Terms<sup>29</sup>*

A **deductible** is the amount a beneficiary owes for covered health care services before the health insurance plan begins to pay.

A **copayment** is a fixed amount the beneficiary pays for a covered health care service, usually at the point of care.

**Coinsurance** is the beneficiary’s share of the costs of a covered health care service, calculated as a percent of the allowed amount for the service.



### ***Cost Sharing in Medicare and Medicaid***

Fee-for-service Medicare includes significant cost-sharing, including copayments and deductibles, and does not protect beneficiaries from catastrophic expenses. This has severe financial implications for seriously ill Medicare beneficiaries, such as those with cancer. A recent study found that out-of-pocket expenses for Medicare beneficiaries with a new cancer diagnosis who lacked supplemental coverage were about one-quarter of their yearly household income, or more than \$8,000 on average.<sup>30</sup> Supplemental coverage through Medigap plans and Medicaid can help defray these out-of-pocket expenses. In the most recently available data, only about 14 percent of Medicare beneficiaries are in fee-for-service Medicare without supplemental coverage.<sup>31</sup>

Most MA plans use copayments and deductibles to reduce utilization, although there is an out-of-pocket cap and overall cost-sharing is typically lower in MA compared to fee-for-service Medicare. Cost sharing is used in Medicaid only in a few rare instances in a small number of states, mostly to deter beneficiaries from using emergency services for non-emergent care.

### ***High-Deductible Health Plans***

High-deductible health plans (HDHPs) use a blunt approach that includes high cost sharing for all services, with little or any adjustments based on the value of services delivered. Of enrollees in Health Insurance Exchange plans, almost 90 percent are enrolled in HDHPs. HDHPs are dominant in non-Exchange individual plans, as well.<sup>32</sup> About one-quarter of employees are currently enrolled in HDHPs, and most employers offer at least one HDHP to employees.<sup>33</sup> A recent study found that HDHPs result in underutilization of needed services, especially for low-income beneficiaries.<sup>34</sup> If individuals with serious illness forgo needed services, pain and other symptoms can go unmanaged, and overall health may decline more rapidly.

HDHPs are often paired with Health Savings Accounts (HSAs), which are tax-exempt accounts that may be used to pay for medical expenses defined by the IRS. Health Reimbursement Accounts (HRAs) are a similar option, in which a company reimburses an individual for their medical expenses. Both options help offset deductibles and copayments in HDHPs, but high out-of-pocket spending can still occur in high-need patients if the HSA is depleted.

### ***Value-Based Insurance Designs***

VBIDs use minimal copayments for high-quality services and providers and higher copayments for low value services and providers. They also may provide direct incentives for beneficiaries to receive health assessments and engage in certain lifestyle changes. In rare cases, they may exempt certain services from being subject to deductibles.<sup>35</sup> This approach is particularly relevant to serious illness care, as patients have complex needs and are not always incentivized to seek the highest value services, such as care planning and palliative care.

The most effective VBIDs are “clinically nuanced,” meaning that cost sharing adjustments applying only to patients with particular conditions that meet certain clinical criteria. A recent study showed that VBIDs can result in overall spending reductions for patients with heart disease and chronic obstructive pulmonary disease (COPD), even while increasing use of certain high-quality services.<sup>36</sup>

There are no surveys of the use of VBID, but it remains rare and limited in scope. Due to the interest in increasing adherence and promoting use of generics, VBID has been used mostly for prescription drugs, although is becoming increasingly common for medical services for chronic conditions. Other uses have focused



on incentives for patient assessments and lifestyle changes. Higher cost-sharing for low value services is extremely rare.<sup>37</sup>

VBIDs are not permitted in Medicare except through a voluntary CMS demonstration model for MA plans in a limited number of states.<sup>38</sup> In the MA VBID model program, which began in 2017, MA plans are able to vary cost sharing for beneficiaries with certain chronic conditions common in the seriously ill, including diabetes, congestive heart failure, stroke, and COPD. Starting in 2018, dementia and rheumatoid arthritis will be eligible diseases, and MA plans in three additional states will be eligible to participate. See Box 6 for a description of UPMC's MA VBID model, which has been identified as an innovative model due to its focus on patients with multiple chronic conditions, rather than a single condition.

#### *Box 6: Case Example: UPMC Medicare Advantage VBID Model and Supplemental Services*

UPMC Health Plan is a participant in the Centers for Medicare & Medicaid Services' (CMS) Value-Based Insurance Design (VBID) model program for Medicare Advantage (MA). Through the MA VBID model, MA providers cannot directly modify cost sharing, but they can provide payments to participants to incentivize them to take certain actions to improve their health. Unique among the CMS VBID model participants, the UPMC model limits eligibility to beneficiaries with more than one chronic condition. Key informants we interviewed who have expertise in VBID models noted that this approach is more likely to generate overall cost savings compared to approaches that include beneficiaries with only one chronic condition.

In the UPMC model, each beneficiary completes a health assessment survey on enrollment. This assessment includes questions about social and medical factors that could impact their health status. Once the survey has been completed, a case manager contacts the beneficiary to discuss lifestyle issues and develop a comprehensive care plan. After the conversation with the case manager, the individual is eligible to earn reimbursement on amounts paid for their deductible and co-payments through completion of quarterly activities, including lifestyle and health management programs.

In addition to the VBID model, UPMC has an Advanced Illness Care (AIC) program for patients with serious illness. Through this supplemental program, beneficiaries receive home visits and palliative care services from nurse practitioners and social workers. A care plan is developed in coordination with the patient's primary care provider that captures patient preferences for care. UPMC is working to streamline handoffs between case managers working with patients in the VBID model and members of the AIC care team, and for the VBID care plan to feed into a patient's AIC care plan. UPMC is also currently designing a version of the AIC program that can be provided through telehealth technologies for beneficiaries in rural areas.

### **Provider Networks**

Provider networks and access to care varies among Medicare, Medicaid, private insurance, and employer-based health insurance. There is often a tradeoff between the network access size and the cost of care. Larger, more open networks increase access to care, but also typically increase overall costs due to the inclusion of higher-cost providers. In more limited networks, access is typically restricted to lower-cost providers.



### ***Narrow and Tiered Networks in Private Plans***

Narrow networks are increasingly common in private plans. About one-fifth of Exchange plan networks are narrow.<sup>39</sup> While narrow networks have shown evidence of reducing costs,<sup>40</sup> they also reduce patient choice and may lead to patients selecting lower-quality providers if the criteria for inclusion in the network is solely based on cost and does not take quality into account.

An approach that addresses this issue is high-performance tiered networks, which include a wider network of providers and tie beneficiary cost sharing to both provider cost and quality. Under this approach, providers that are the highest value are in the highest tier, and providers that are the lowest value are in the lowest tier.<sup>41</sup> A small but growing minority (17%) of employers are offering high-performance tiered networks, including about one-quarter of large employers.<sup>42</sup>

### ***Provider Networks in Medicare and Medicaid***

In fee-for-service Medicare and Medicaid, there are no network restrictions on provider access, so long as a particular provider participates in the program. Medicaid MCOs and MA plans, in contrast, typically have limited provider networks. For example, a recent study found that only one in four MA plans include a broad network of hospitals in-network, compared to about half of Exchange plans.<sup>43</sup> Narrow hospital networks can result in unanticipated out-of-pocket expenses, especially for the seriously ill. Individuals with serious illness may not have the ability or capacity to choose the services of in-network providers, especially in emergency situations.

## ***Discussion***

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Our review of the current state of health benefits for serious illness care suggests that the current system works for some, but does not work well for many others. Importantly, conditions and circumstances can change rapidly, creating a precarious situation for all patients and families. An individual for whom the system works well could have a change in insurance status, for instance, and immediately face significant barriers to accessing needed services.

### **Stakeholders That Win Under the Current System**

1. *Private plans.* Private insurers have many options for limiting access to costly services for the seriously ill through coverage decisions, cost-sharing, and network design. In addition, employer-based, Exchange, and other individual plans benefit from having older, high-risk patients become eligible for Medicare, leaving them with a relatively younger, healthier risk pool. Most individuals with serious illness are in governmental programs, or managed care plans within those programs.
2. *Individuals who can afford generous LTC insurance.* LTC insurance is rarely provided by employers. Individuals who need and can afford LTC insurance can use it to finance HCBS while they receive medical services from their employer-sponsored health insurance or Medicare. However, LTC insurance often has many exceptions to coverage and may not cover the needs of seriously ill individuals. Only generous (and more expensive) plans cover comprehensive HCBS services.
3. *Certain Medicare Advantage members.* MA plans offer relatively comprehensive benefits for the seriously ill, especially considering enhanced programs like UPMC's Advanced Illness Care program. However, MA members do face barriers such as narrow networks and pre-authorization, and the



hospice carve-out creates fragmentation that can result in poorly coordinated care and delays in receiving hospice services.

4. *Employees of forward-looking companies.* Many large employers offer generous benefit packages that include a comprehensive set of medical services. However, only a very small (but growing) number of companies, such as Deloitte, offer caregiving benefits.

### Stakeholders That Lose Under the Current System

1. *Middle-income individuals.* People who are younger than 65 and middle income may find themselves covered by a HDHP, and may have to pay an unaffordable deductible to receive needed services. Middle-income individuals do not qualify for Medicaid and may not be able to afford LTC insurance.
2. *Medicare beneficiaries without supplemental coverage.* Fee-for-service Medicare beneficiaries with serious illness who do not have a supplemental plan can face significant out-of-pocket spending due to cost sharing and the lack of an out-of-pocket maximum.
3. *Individuals transitioning across payers.* People who are transitioning between payers, whether it be changing employers, entering Medicare, or churning in or out of Medicaid, often face significant changes in benefits and cost sharing. These changes are difficult regardless of health status, but can be particularly confusing for individuals with serious illness and their families.
4. *Medicaid beneficiaries in states with limited HCBS.* While all states provide HCBS through their Medicaid programs, the benefit is not as widely available in some states as it is in others. For example, some states only provide HCBS to certain eligibility groups.<sup>44</sup> In other states, financial eligibility is more restrictive than for other Medicaid services, and enrollment limits result in waiting lists for services.<sup>45</sup>
5. *Family caregivers.* While there are a few notable examples, caregiving benefits outside of respite care are rare. Family caregivers will continue to face financial, as well as emotional, burdens of providing care to their loved ones with serious illness without additional support.

### Recommendations

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Building on the findings of our assessment, we developed a set of benefits-related recommendations that would promote increased innovation, access to community-based serious illness care, and support for patients and their caregivers. These recommendations focus primarily on policy changes, and address needed research and evidence generation.

① *Recommendation*

**Increase flexibility for Medicare Advantage plans**

MA plans are unable to utilize VBID outside of the CMS demonstration program. The CHRONIC Care Act, which was passed by the Senate in October 2017, would permit MA plans to implement benefit structures that vary benefits, cost-sharing, and supplemental benefits for enrollees with certain chronic diseases.<sup>46</sup> This policy was also included in the Better Way platform put forward by Speaker of the House Paul Ryan in 2016,<sup>47</sup> and is included in the V-BID for Better Care Act, which is bipartisan legislation in the House of Representatives.<sup>48</sup> Giving MA plans more flexibility in cost-sharing structures would promote innovation.

In addition to being permitted to implement VBID more broadly, MA plans should be permitted to collaborate with hospice providers. Currently, hospice services are “carved-out” of MA, meaning that when an MA beneficiary needs hospice services, they revert to fee-for-service Medicare. About half of MA beneficiaries ultimately use hospice services, and the carve-out results in hundreds of thousands of MA beneficiaries reverting to fee-for-service Medicare each year. The carve-out creates fragmentation in care and limits innovation. If hospice services were carved-in to MA, plans could test innovative approaches, such as providing the benefit earlier in a patient’s care, rather than at the very end of life.

In addition, MA plans are currently not permitted to offer LTSS benefits. A recent study by the Bipartisan Policy Center assessed the cost and feasibility of allowing MA plans to offer a limited benefit for LTSS.<sup>49</sup> Their analysis suggested that a benefit with a \$75 per day maximum would have a premium of \$35 to \$40 per member per month.

② *Recommendation*

**Promote VBID in private plans through an IRS “safe harbor”**

VBIDs remain relatively uncommon in private health plans. As noted in the paper, reducing deductibles and copayments for high-value services for the chronically ill has been shown to reduce spending. Efforts should be taken to promote expanded use of VBIDs in private insurance. The administrative complexity of implementing VBID structures is likely one reason for their low use, but there are policy barriers, as well.

The IRS has established a safe harbor for preventive services in HSA-eligible HDHPs. Through the safe harbor, these preventive services are exempt from deductibles. However, current regulations do not permit deductible exemptions for HDHP or other private plan coverage of other services, such as high-value services for chronic conditions. Expanding the safe harbor to include such services would help spur more VBIDs in private insurance for increased use of evidence-based services among the seriously ill.

**③ Recommendation**

**Allow retirement savings to be used to purchase long-term care insurance**

Purchase of private LTC insurance remains rare, despite the increasing need for long-term care and HCBS in particular. A major reason that few individuals purchase comprehensive LTC insurance is cost. To increase affordability, individuals could be permitted to make penalty-free early withdrawals from retirement savings accounts to purchase LTC insurance. A recent analysis found that this policy would result in 8.5 million new LTC insurance enrollees.<sup>50</sup>

**④ Recommendation**

**Provide federal income tax credits for family caregiving**

Bipartisan federal legislation called the Credit for Caring Act was introduced in 2016 to provide tax credits to family caregivers. Under this proposed law, qualifying caregivers would receive a tax credit for 30 percent of qualified expenses above \$2,000 to provide care to a family member, up to a maximum credit amount of \$3,000. While the benefit is relatively small, it would provide much needed financial support to family members who may be foregoing income or spending out-of-pocket to care for their loved one.

**⑤ Recommendation**

**Conduct research on employer-based caregiving benefits**

Widespread provision of employer-based benefits for caregiving is unlikely without additional evidence. The recent AARP survey of employers on caregiving issues found that nearly 80 percent of employers believe a business case with return on investment information is needed to expand caregiving benefits.<sup>51</sup> Employers need to have evidence that the costs of these benefits will be outweighed by improvements in employee morale, reductions in absenteeism, and positive impacts on recruitment and retention. Conducting research on innovative approaches like Deloitte's will generate this evidence and help employers make more informed decisions about caregiving benefits moving forward.

## **Conclusion**

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Seriously ill individuals need a wide range of services across many different settings of care, including non-medical services in the community. The benefits available to the seriously ill differ greatly across private plans and government programs. Overall, the benefit structures are complex, difficult to navigate, and too often limit access to needed services. While seriously ill individuals with LTC insurance and Medicare beneficiaries with supplemental plans or MA are relatively advantaged in the current system, lower income individuals and their caregivers face significant challenges.

Evidence suggests that there are promising models for expanding access to needed services while still placing downward pressure on spending. Policy changes, such as expansion of the MA VBID model and expansion of IRS



safe harbors, would encourage additional innovation by health plans. Other steps can be taken to encourage individual purchase of LTC insurance and provide additional benefits to support caregivers.



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