

Medicare and Family Caregivers

June 2020

Introduction

The *RAISE Family Caregivers Act*, Public Law 115-119 (1/22/2018) directs the Department of Health and Human Services to develop and maintain a national family caregiver strategy that identifies actions and support for family caregivers in the United States. Over 62 million Americans¹ who are 65 or older, and certain younger people with significant disabilities, rely on Medicare for health care coverage and access to care. Many Medicare beneficiaries² depend on family members to provide or supplement their care. Thus, Medicare's role in providing personal care and supporting family caregivers is important to effectuate the RAISE Act.

Medicare was enacted in 1965 as Title 18 of the Social Security Act. Like Social Security, Medicare was envisioned and designed as social insurance, in which all who qualify contribute and benefit universally. Before Medicare, 48% of Americans 65 and older had no insurance.³ With Medicare, most Americans in this cohort are insured.⁴ Coverage is similar to that provided by private insurance – Medicare pays a portion of the cost of some health care. Premiums, deductibles and cost-sharing are required of beneficiaries. Since Medicare is a national program, coverage shouldn't vary significantly from state to state. However, the original vision of Medicare as a national social insurance program has changed, as myriad private plans and income-based premiums have been added to the program.

This Issue Brief examines the role Medicare currently plays, and could play, in assisting beneficiaries and their family caregivers. As the population ages, and lives longer with chronic conditions, the need for family caregiving, and support for caregivers, is increasing. Concurrently, however, access to Medicare-covered home health aide care continues to decline.⁵ This is often true even for individuals who meet the Medicare law's qualifying criteria. Unfortunately, Medicare beneficiaries are often given inaccurate information regarding Medicare home health coverage in general, and home health aides in particular. Sometimes they are told Medicare simply does not cover home health aides. Harmful misinformation abounds.

Further compounding this problem, **Medicare does not provide coverage for family caregivers.** Coverage is only available for personal care through home health aides, provided through a Medicare-certified home health agency; the individual must have an authorized practitioner's order, be homebound, and need nursing or physical or speech therapy.⁶ While Medicare hospice coverage does include some limited respite coverage for caregivers, that benefit is only available for beneficiaries who are terminally ill and elect the hospice benefit.⁷

Privately paying for in-home care/aides can cost around \$3,000 per month,⁸ unaffordable for most Medicare beneficiaries. Basic facts about the Medicare population tell us why. Half of all Medicare beneficiaries live on annual incomes less than \$29,650; 25% live on annual incomes below

\$17,000; 50% have savings less than \$73,800; 10% have no saving or are in debt. Data also shows that beneficiaries of advanced age and younger beneficiaries with disabilities have yet lower incomes:

Among people ages 65 and older, median per capita income declined steadily with age, dropping from \$35,200 between ages 65 to 74 to \$22,750 at ages 85 and older. Across the entire Medicare population, median per capita income was considerably lower for beneficiaries under age 65 with permanent disabilities (\$19,550) than among seniors. In 2018, about one in seven (15%) of Medicare beneficiaries were under age 65 and generally eligible for Medicare due to a long-term disability. Median income for individuals ages 65 and older was \$31,450 per person in 2019, while one in four beneficiaries ages 65 and older had incomes below \$18,150.⁹

Thus, out-of-pocket health costs, including for in-home care, often pose an access barrier, particularly for beneficiaries in fair or poor health.¹⁰ When Medicare coverage is unavailable or unfairly denied, beneficiaries are often unable to afford the home care they need. This places additional, avoidable stress on the beneficiary, family, and family caregivers. Unable to live safely in the community, it may also lead to preventable health complications, injuries, hospitalizations, and nursing home admissions.

A. Medicare Home Health Care Coverage

Medicare home health coverage can be an important source of financing for Medicare beneficiaries who need health care at home. To address the increasing need for home care and family support, and to consider possible solutions, one must first understand what Medicare coverage should be available under the law.

When properly implemented, the Medicare home health benefit provides coverage for a constellation of skilled and nonskilled services. Coverage is available for people with acute and chronic conditions, for skilled care to maintain or slow decline, and even if the services are expected to extend over a long period of time.¹¹ However, even people with Medicare have difficulty obtaining and affording necessary home care. While there are legal standards that define who can obtain coverage, and for what services, the criteria are often narrowly construed and misrepresented, resulting in inappropriate barriers to Medicare and necessary care. This is increasingly true for home health aide services – the very kind of personal care services family caregivers are called on to provide, and the help both patients and caregivers need.

B. The Law: What Home Care Is Covered Under the Medicare Act?¹²

Home health access problems have ebbed and flowed over the years, depending on the reigning payment model, systemic pressures, and misinformation about Medicare home health coverage. Regrettably, it appears these problems are increasing and, if current and proposed policies and practices continue, they will only get worse. Accordingly, it is important to know what Medicare home health coverage should be under the law, especially for people with long term, chronic, and debilitating conditions.

1. Medicare Home Health Qualifying Criteria

Medicare provides for coverage of home health services under Parts A and B when the services are medically “reasonable and necessary,” and when:¹³

- A physician or other authorized practitioner has established a plan of care for furnishing the services that is periodically reviewed as required;
- The individual is confined to home (commonly referred to as “homebound”). This criterion is generally met if non-medical absences from home are infrequent and leaving home requires a considerable and taxing effort, which may be shown by the patient needing personal assistance, or the help of a wheelchair or walker, etc. Occasional "walks around the block" are allowable. Attendance at an adult day care center or religious services is not a bar to meeting the homebound requirement;
- The individual needs skilled nursing care on an intermittent basis, or physical or speech therapy or, in the case of an individual who has been furnished home health services based on such a need, but no longer requires skilled nursing care or physical or speech therapy, the individual continues to need occupational therapy; and
- Such services are furnished by, or under arrangement with, a Medicare-certified home health agency.¹⁴

2. Medicare Covered Home Health Services

If the qualifying conditions described above are satisfied, Medicare coverage is available for an array of home health services. Home health services that can be covered by Medicare include:¹⁵

- Part-time or intermittent nursing care provided by or under the supervision of a registered professional nurse;
- Physical therapy, speech language pathology (speech therapy), and occupational therapy;
- Part-time or intermittent services of a home health aide;
- Medical social services; and
- Medical supplies.

As described above, skilled nursing, physical therapy, and speech language pathology services are defined as “qualifying skilled services” for the purpose of establishing eligibility for Medicare home health coverage.¹⁶ A patient must initially require and receive one of these skilled services in order to receive Medicare for other covered home health services.¹⁷ Home health aide, medical social worker, and occupational therapy services¹⁸ are defined as “dependent services,” along with certain durable medical equipment and medical supplies.¹⁹ While occupational therapy is not considered a skilled service to begin Medicare home health coverage, if the individual was receiving skilled nursing, physical or speech therapy, but those services end, coverage can continue if occupational therapy continues.²⁰

Medicare threshold requirements are key. The patient must be confined to home (“homebound”) and require a qualifying skilled service provided under a plan of care. If these preconditions are met, the beneficiary often qualifies for Medicare home health coverage for necessary skilled services and “dependent” services, including home health aides.²¹ Even for those who meet these

requirements, however, there are important gaps in the Medicare home health aide benefit. Home health aides must be provided by, or under arrangements with, a Medicare-certified agency.²² Homemaker services are not covered unless those services are “incidental” to the personal care provided by home health aides.²³ Medicare coverage is not available at all for family caregivers.

Contrary to what is often heard, however, Medicare home health coverage is not just a short-term, acute care benefit.²⁴

There is No Duration of Time Limit for Medicare Home Health Coverage

So long as the law’s qualifying criteria are met, coverage can continue for an unlimited number of visits. “to the extent that all coverage requirements specified in this subpart are met, payment may be made on behalf of eligible beneficiaries ... for an unlimited number of covered visits.”

(42 CFR §§409.48(a)-(b); Medicare Benefit Policy Manual, Chapter 7, §70.1)

C. The Reality: Access to Medicare Coverage and Home Care is Limited

The Center for Medicare Advocacy hears regularly from people who meet Medicare coverage criteria, but are unable to access Medicare-covered home health care, or the appropriate amount of care.

In particular, people living with long-term and debilitating conditions find themselves facing significant access problems. For example, patients have been told Medicare will only cover one to five hours per week of home health aide services, or only one bath per week, or that they aren’t homebound (because they roam outside due to dementia), or that they must first decline before therapy can commence (or recommence). Consequently, these individuals and their families struggle with too little care, or no care at all.

As reported in *Health Affairs* in November 2019:²⁵

When asked how much costs had burdened their family, 25 percent of the seriously ill said that costs were a major burden, and 30 percent said that they were a minor burden... When asked about getting help in recent years, 60 percent said that family members and friends helped a lot, 25 percent said that they helped a little, and 14 percent said that they provided no help. Family members and friends experienced considerable strain as a consequence of providing help, including financial problems, lowered income, and lost or changed jobs or reduced hours. Twenty-nine percent of respondents said that there was a time when they did not get outside help because of cost.

The Center for Medicare Advocacy has been contacted about Medicare beneficiaries from all over the country who are trying to obtain sufficient home health care to help improve or maintain their condition and remain safely at home. Here is one example that typifies what we hear:

- My dad is in the end stages of Parkinson's disease and has qualified for home health aide care for 2 hours per week through Medicare. He actually should have 24/7 care, however, the financial burden for paying for home health care is too much for us - and the average family. We were shocked to learn that Medicare only covers a few hours per week and would like to see changes to allow more coverage for individuals living with a long term, progressive terminal disease.

As geriatrician Dr. Laurie Archbald-Pannone states, “While family caregivers truly do selflessly give of themselves in the care of others, they need more than our recognition of their work. They need the Medicare system to provide appropriate resources for the care of their family members.”²⁶ (Emphasis added.)

D. Access to Medicare-Covered Home Health Aides is Shrinking

Help with personal hands-on care is key to the well-being of patient and caregiver alike. Unfortunately, access to Medicare coverage for such care has declined. This is true even when individuals have an order and meet the law’s homebound and skilled care requirements – and thus qualify for coverage. Unfortunately, Medicare beneficiaries are often misinformed. They are told they can only get home health aides a few times a week, for a short time, and/or only for a bath. Sometimes they are told Medicare simply does not cover home health aides. The Center for Medicare Advocacy has even heard of an individual being told he could not receive home health aide coverage because he was “over income” – although Medicare has no income limit.

Under the law, Medicare authorizes up to 28 to 35 hours a week of home health aide (personal hands-on care) and nursing services combined.²⁷ While personal hands-on care does include bathing, it **also** includes dressing, grooming, feeding, toileting, and other key services to help an individual remain healthy and safe at home.²⁸

In the past, this level of home health aide coverage was actually available. As noted below, the Center for Medicare Advocacy has helped many clients remain at home because these services were in place; currently such coverage and care is almost never obtainable. Data demonstrate this point. In 2019 the Medicare Payment Advisory Commission (MedPAC) reported that home health aide visits per 60-day episode of home care declined by 88% from 1998 to 2017, from an average of 13.4 visits per episode to 1.6 visits. As a percent of total visits from 1997 to 2017, home health aides declined from 48% of total services to 9%.²⁹

The real, personal, impact of this reduced access to home health aides was highlighted in a 2019 *Kaiser Health News* article.³⁰ The article includes stark findings about the unmet needs of vulnerable Americans struggling to live at home with little or no help. For example:

- “About 25 million Americans who are aging in place rely on help from other people and devices such as canes, raised toilets or shower seats to perform essential daily activities, according to a new study documenting how older adults adapt to their changing physical abilities.”
- “Nearly 60 percent of seniors with seriously compromised mobility reported staying inside their homes or apartments instead of getting out of the house. Twenty-five

percent said they often remained in bed. Of older adults who had significant difficulty putting on a shirt or pulling on undergarments or pants, 20 percent went without getting dressed. Of those who required assistance with toileting issues, 27.9 percent had an accident or soiled themselves.”

- “60 percent of the seniors surveyed used at least one device, most commonly for bathing, toileting and moving around. (Twenty percent used two or more devices and 13 percent also received some kind of personal assistance.)” and
- Five percent had difficulty with daily tasks but didn’t have help and hadn’t made other adjustments yet.”

While it isn’t clear how many of these individuals should have been helped through Medicare, it is likely that far more qualify than are able to access the benefit, since the surveyed population was 65 or older and infirm. Indeed, the author states “The problem, experts note, is that Medicare doesn’t pay for most of these non-medical services, with exceptions.”³¹

In fact, the problem is more complex. The Medicare home health benefit is misunderstood, inaccurately articulated, and narrowly implemented. Medicare-certified home health agencies have all but stopped providing necessary, legally authorized home health aide services, even when patients are homebound and are receiving the requisite nursing or therapy to trigger coverage. The Centers for Medicare & Medicaid Services (CMS) does not monitor or rebuke agencies for failure to provide this mandated and necessary care.

As Dr. Laurie Archbald-Pannone notes,

“As a geriatrician, every week I see patients who are fortunate enough to have family who are able to provide medical care and support. However, I also see more patients who do not have family available to provide full care, are in desperate need of more home care support, but cannot afford the price tag ... Without in-home care, we’re leaving our family members alone and at risk. ... We may not be available to stay home with them, but Medicare should support trained care aides who can be.”³²

As is commonly expressed, “*there’s no free lunch.*” When Medicare doesn’t cover in-home care, patients and families often go without, those who can, pay out-of-pocket, from savings, or credit cards. Others, who are, or become, poor (often due to health care costs) look to their state’s low-income Medicaid program for help. Thus, costs are regularly shifted to people in need and, for those who are dually eligible for Medicaid as well as Medicare, to Medicaid programs. The needs and costs of caring for people who are dually eligible are substantial:

In 2018, there were 12.2 million individuals simultaneously enrolled in Medicare and Medicaid. These dually eligible individuals experience high rates of chronic illness, with many having long-term care needs and social risk factors. Forty-one percent of dually eligible individuals have at least one mental health diagnosis, 49 percent receive long-term care services and supports (LTSS), and 60 percent have multiple chronic conditions. Eighteen percent of dually eligible individuals report that they have “poor” health status, compared to six percent of other Medicare beneficiaries.³³

In summary, as the authors in the November, 2019 *Health Affairs* article concluded: ³⁴

“Medicare insurance is broadly popular, but seriously ill beneficiaries who most need financial protection report widespread problems affording care and financial instability.”

1. Impact of Caregivers on Access to Medicare Home Health Coverage

Medicare does not cover or help pay for family caregivers, but the fact that caregivers are – or are not – available, willing, or able to provide needed care frequently interferes with a beneficiary’s ability to obtain Medicare covered in-home care. On the one hand, beneficiaries and their families may be told that a home health agency will not provide care because it is not safe for the individual to be home since there is no caregiver available. On the other hand, when caregivers are available, patients may be told that, as a result, Medicare will not cover in-home care since that caregiver should provide the care.

In fact, neither of these is true. Medicare coverage is not dependent on whether there is or is not a family caregiver – or other caregiver – available. Medicare beneficiaries are eligible for Medicare-covered home care regardless of whether they do or do not have family or other caregivers in place.

CMS Benefit Policy Manual, Chapter 7

20.2 - Impact of Other Available Caregivers and Other Available Coverage on Medicare Coverage of Home Health Services (Rev. 208, Issued: 04-22-15, Effective: 01-01-15, Implementation: 05-11-15) Where the Medicare criteria for coverage of home health services are met, patients are entitled by law to coverage of reasonable and necessary home health services. Therefore, a patient is entitled to have the costs of reasonable and necessary services reimbursed by Medicare without regard to whether there is someone available to furnish the services. However, where a family member or other person is or will be providing services that adequately meet the patient's needs, it would not be reasonable and necessary for HHA personnel to furnish such services. Ordinarily it can be presumed that there is no able and willing person in the home to provide the services being rendered by the HHA unless the patient or family indicates otherwise and objects to the provision of the services by the HHA, or unless the HHA has first-hand knowledge to the contrary.

EXAMPLE 1: A patient who lives with an adult daughter and otherwise qualifies for Medicare coverage of home health services, requires the assistance of a home health aide for bathing and assistance with an exercise program to improve endurance. The daughter is unwilling to bathe her elderly father and assist him with the exercise program. Home health aide services would be reasonable and necessary. ...

EXAMPLE 3: A patient who needs skilled nursing care on an intermittent basis also hires a licensed practical (vocational) nurse to provide nighttime assistance while family members sleep. The care provided by the nurse, as respite to the family members, does not require the skills of a licensed nurse (as defined in §40.1) and therefore has no impact on the beneficiary's eligibility for Medicare payment of home health services even though another third party insurer may pay for that nursing care.

As federal regulations state, among other requirements, services must “[b]e of a type that there is no able or willing caregiver to provide, or, if there is a potential caregiver, the beneficiary is unwilling to use the services of that individual.”³⁵ Indeed, CMS’s own Medicare Policy Manual confirms that beneficiaries are entitled to have the costs of reasonable and necessary services reimbursed by Medicare without regard to whether there is someone available to furnish the services. The CMS Policy Manual states, “ordinarily it can be presumed that there is no able and willing person at home to provide services rendered by the home health aide or other home health personnel.” (Emphasis added.)³⁶

E. Medicare’s Home Health Payment System Influences Access to Care

On January 1, 2020, CMS implemented a new Medicare payment system for home health services called the “Patient Driven Groupings Model” (PDGM). PDGM changed home health agencies’ financial incentives and disincentives to admit or continue care for Medicare beneficiaries.³⁷ Unfortunately, the financial motivations are often harmful to vulnerable beneficiaries, particularly those with chronic conditions and longer-term health care needs.

PDGM’s financial incentives include higher rates for the first 30 days of home care. Payments are also higher for beneficiaries who are admitted after an inpatient institutional stay (hospitals and skilled nursing facilities), and lower for those admitted from the community. (The “community” category includes hospital outpatients, including hospital patients in “Observation Status,” as well as patients who start care from home, without a prior hospital or SNF stay.) The new payment model also reduced the billing period from 60 days to 30 days, and lowered the financial incentive to provide therapy by removing therapy service utilization payment thresholds.

The new Medicare payment system and shift in financial incentives have reduced access to necessary care. For instance, a *Home Health Care News* article states that “[s]tories of widespread layoffs of PTs, OTs and SLPs persist — and now new reports of agencies incorrectly telling their patients that Medicare no longer covers therapy under the home health benefit...”³⁸ Reductions in skilled therapy does not only harm the individual who needs that care, it can also end access to home health aides since aide services are dependent on the individual receiving skilled therapy or nursing.

In response to misinformation and service changes in light of PDGM, CMS released a special edition *Medicare Learning Network (MLN) Matters* article on February 10, 2020.³⁹ The MLN made clear that, while the reimbursement system had changed:

“... [E]ligibility criteria and coverage for Medicare home health services remain unchanged. ... as long as the individual meets the criteria for home health services as described in the regulations at 42 CFR 409.42, the individual can receive Medicare home health services, including therapy services. ... Citing to the [Jimmo v. Sebelius Settlement Agreement](#), the MLN also states “there is no improvement standard under the Medicare home health benefit and therapy services can be provided for restorative or maintenance purposes.” (Emphasis added.)

Thus, as recently as February 2020, CMS reiterated the following

- Medicare home health coverage and service rules have not changed;
- Home health services can continue as long as individuals meet the Medicare coverage criteria; and
- Beneficiaries can receive home health services to improve their condition, and to maintain their current condition, or to slow or prevent further decline.

F. Medicare Advantage: Limited In-Home Care Benefit Available to Certain Enrollees

Medicare Advantage (MA) plans must offer all services that are covered under Medicare Parts A and B, including home health.⁴⁰ In addition to services that MA plans must cover, plan sponsors have long had the ability to offer supplemental benefits that are not covered by traditional Medicare. Plans provide such benefits using “rebate” dollars from the Medicare program based upon their annual bid, or by charging additional premiums for optional supplemental benefits.⁴¹ Traditionally, this has included services such as vision, hearing, and dental care.⁴²

Both Congress and CMS have recently expanded the scope of supplemental services that MA plans can provide, including an expansion of the types of services that are considered “primarily health-related” as well as services targeted towards certain plan enrollees deemed to be chronically ill (known as Special Supplemental Benefits for the Chronically Ill (SSBCI)).⁴³ While Dual-Eligible Special Needs Plans (D-SNPs) have had the option to provide non-skilled support services for several years,⁴⁴ these recent changes allow all types of MA plans to cover non-skilled home health aide services without any requirement that an individual be homebound.

In April 2018, CMS issued a memorandum that included a non-exhaustive list of “allowable supplemental benefits resulting from CMS’s reinterpretation of the definition of ‘primarily health related’” which included “In-Home Support Services.”⁴⁵ Such services are defined as those provided “to assist individuals with disabilities and/or medical conditions in performing ADLs and IADLs within the home to compensate for physical impairments, ameliorate the functional/psychological impact of injuries or health conditions, or reduce avoidable emergency and healthcare utilization. Services must be provided by individuals licensed by the state to provide personal care services, or in a manner that is otherwise consistent with state requirements.”⁴⁶ So far, of the plan sponsors that have chosen to offer supplemental benefits under these new flexibilities, home health aide type care is not a widely offered benefit. According to one home health industry publication, in 2020 there are “a couple hundred plans covering-in home care” while “there are 2,000 or so covering transportation or meals under the primarily health-related pathway.”⁴⁷

As described in the following chart, such in-home services, when available, are generally limited, for example, to a set number of visits after discharge from a hospital or nursing facility, or up to once a month for individuals with certain qualifying conditions, at the discretion of the plan.

EXAMPLE: In-Home Support Available Through MA Plans, Los Angeles County, 2020

Using data available on the Medicare Plan Finder [website](#), the Center for Medicare Advocacy analyzed Medicare Advantage (MA) plans available in L.A. County in 2020. Of the 53 non-Special Needs Plans available, roughly 8 plans – offered by 2 plans sponsors (Anthem and WellCare) – were listed as providing any “In Home Support.” Here is a summary of what the plans offer:

- Anthem - Upon discharge from a hospital or nursing facility, enrollees can, upon prior authorization, receive up to 4 (or up to 8, depending on the plan) four-hour shifts of assistance in performing activities of daily living (ADLs); activities include support such as light cleaning or help obtaining groceries outside the home. Not tied to chronic condition.
- WellCare – If enrollees meet certain clinical criteria, subject to prior authorization, the plan can offer access to services, including light cleaning, household chores and meal preparation. Services must be recommended or requested by a licensed plan clinician or a licensed plan provider. Enrollees may participate in care management or be assessed by a care manager. Up to 12 visits a year, and services will be provided in 2-hour increments.

<https://www.medicare.gov/plan-compare/#/?lang=en>

Because of the way that some of these flexibilities are arranged and what is (and is not) required to be reported by plans, the public does not have a handle on how many people are actually able to access such benefits. According to Health Management Associates, “[a]pproximately 4.5 million individuals (19% of total 2020 MA enrollment) in a small number of geographies are enrolled in plans offering at least one new supplemental benefit flexibility” but that “the proportion of enrollee population that qualifies for these new benefits are unknown, since plans may tailor benefits to certain enrollees with plan-specific policies and processes to extend them to eligible enrollees.”⁴⁸

While the fact that at least some MA plans are offering limited benefits to provide in-home, unskilled care is clearly a recognition of the need, there are a number of reasons why the Medicare Advantage program should not be relied upon as the avenue to provide widespread assistance to caregivers.

First, because in-home support services (not attached to the home health benefit) are not covered by traditional Medicare, provision of such services is entirely voluntary and at the discretion of a given MA plan. MA plans can change their benefit packages on an annual basis. While MA plans have significant funding – as discussed further below – the funds from which they draw to provide supplemental benefits is also used to provide popular services such as vision, hearing and dental services so there is built in competition for how plans choose to allocate their rebate dollars, and incentives to offer in-home care might be diminished.⁴⁹

Second, in addition to such benefits being offered entirely at the discretion of plan sponsors, variability in payments to plans will inevitably lead to variability in where such benefits are offered, creating uneven access to services. As noted by the Urban Institute in a 2019 report,

“[b]ecause rebate amounts vary substantially across the country, the opportunity to add supplemental benefits addressing enrollees’ health-related social needs will be uneven” and such benefits “will always vary geographically.”⁵⁰ Further, as raised by consumer advocates, Urban also notes that “[b]ecause of geographic variation in MA and plans’ ability to target benefits based on health conditions, it will also be difficult to make benefit eligibility clear and market these benefits fairly to consumers.”⁵¹

Third, the Medicare Advantage program is overpaid relative to what is spent on traditional Medicare, thus current spending on supplemental benefits may not be sustainable. While the Affordable Care Act (ACA) reined in much of the overpayments, MA plans are still paid, on average, more per enrollee than the traditional Medicare program spends on a given beneficiary due, in part, to a quality bonus payment system for which most plans qualify, and to manipulation of risk scores.⁵²

Finally, as a matter of equity, services that can help caregivers should be available to all Medicare beneficiaries, not just a subset who choose to enroll in private plans.⁵³ While MA enrollment is growing, the majority of Medicare beneficiaries – 64% in 2020⁵⁴– choose to remain in the traditional Medicare program. If the Medicare program was expanded to include services aimed at helping caregivers, such benefits would become part of Medicare’s baseline coverage, which would, in turn, have to be covered by MA plans, thus providing benefits to everyone, regardless of how they choose to obtain their Medicare coverage.

In short, Medicare Advantage is not the panacea for what ails or is missing from the Medicare program. As discussed next, broad-based solutions are required that would accrue to the benefit of all beneficiaries.

G. Recommendations / Possible Next Steps

The bipartisan Federal Commission on Long-Term Care (hereinafter “LTC Commission”) was charged by Congress with developing recommendations for the establishment, implementation, and financing of a comprehensive, coordinated, and high-quality system that ensures the availability of long-term services and supports for individuals who depend on this system to live full and healthy lives.⁵⁵ Over several months in 2013, the LTC Commission met, and after the majority reached its conclusions, five of the Commissioners (including Center for Medicare Advocacy Executive Director Judith Stein, co-author of this paper), issued an Alternative Report and Recommendations to fulfill this comprehensive charge (hereinafter referred to as “Alternative Report”).⁵⁶

The Commissioners who drafted the Alternative Report stated that “We are convinced that no real improvements to the current insufficient, disjointed array of LTSS and financing can be expected without committing significant resources, instituting federal requirements, and developing social insurance financing.” The Report noted that “[w]hile the nation moves to a comprehensive system for LTSS, and to supplement it as necessary, we recognize that improvements are needed in current programs.” Among the recommendations offered, was “[t]o meet the needs of those who qualify for Medicare, the current Medicare program must be adapted to reduce counterproductive,

outdated and unreasonable barriers to outpatient therapies, home health and skilled nursing facility care.”

As detailed above, Medicare does not cover family caregivers or non-skilled home care alone, only when skilled care is also required. Below we explore three broad areas of recommendations to improve this situation, some of which were discussed in the LTC Commission Alternative Report.

Recommendations

1. Ensure the scope of current allowable home health benefits, generally, and home health aides, specifically, are actually provided. Simply put, ensure that current law is followed;
2. Create a new stand-alone home health aide benefit that would provide coverage without the current skilled care or homebound requirements, using Medicare’s existing infrastructure as the vehicle for the new coverage; and
3. Identify other opportunities for further exploration within and without the Medicare program, including additional Medicare revisions, demonstrations, and initiatives overseen by the Center for Medicare and Medicaid Innovation (CMMI).

1. Ensure the Full Scope of Medicare-Covered Services Are Actually Available for All Beneficiaries

As discussed above, there is a growing disconnect between what Medicare home care is coverable under the law, and what is actually available in practice.⁵⁷ In particular, access to Medicare-covered home health aide services has greatly declined, even when individuals meet the law’s qualifying criteria. This is due to a combination of factors, including changes in provider payment incentives and the perpetuation of myths such as the “improvement standard,” despite court orders in the *Jimmo* litigation.

In order to ensure that the law is followed, CMS should take several steps. As discussed above, in response to misinformation about and changes in the way providers are offering services in light of PDGM, CMS issued a special MLN article in February 2020. The MLN reminded providers that eligibility criteria for home health services “remain unchanged” and reiterated that there is no applicable improvement standard.⁵⁸ Individuals who are homebound and receiving skilled care pursuant to a doctor’s order should be able to receive the full array of care authorized by law so long as they meet the qualifying criteria. While welcome, the MLN has not reversed the growing trend limiting access to home care. Additional action is needed.

CMS should revamp the Medicare payment system to create incentives for home health agencies to provide the full extent of services available under the law. Further, it should oversee home health agencies to ensure they are adequately staffed and able to provide the complete array of Medicare-covered home health services. It should actively monitor and publicly report on the provision of home health aide services. CMS should engage in an extensive education program targeting both providers (including home health agencies, prescribing physicians and other clinicians), and Medicare beneficiaries about the legal scope of the home health benefit, including the availability

of skilled and non-skilled care for those who qualify. When necessary, CMS should require corrective action plans from providers that do not have sufficient staff or do not provide appropriate skilled and home health aide services.

Congress should address the lack of access to Medicare-covered home care, and home health aides in particular. This could include hearings or other investigative actions (such as directing reports by the General Accounting Office or the Department of Health and Human Services' Office of Inspector General), to ensure CMS and Medicare-certified home health agencies are interpreting and administering the current home health benefit as provided by law. Congress could also commission studies to explore how proper implementation of the home health benefit would help prevent institutionalization, avoid unnecessary cost-shifting to the Medicaid program, and reduce stress on family caregivers. Although such efforts to enforce the law need not require additional legislation, Congress should consider what is required to guarantee beneficiaries obtain the full Medicare home health coverage for which they qualify. In the table below, a few of the Center's clients are profiled,⁵⁹ highlighting that fully implementing existing law can help many people, even with serious, debilitating conditions, out of institutions and safely at home.

Medicare Home Health Care Can Provide a Long-Term Lifeline

Over the years, the Center for Medicare Advocacy has represented numerous individuals to enable them to obtain, and maintain, home health coverage to stay home with necessary care. With the receipt of Medicare-covered skilled nursing and/or therapy and home health aides, some of our clients have been able to remain home for years. Here are a few examples:

- Ms. B (CT) – From 1987 until her death in 2015, at age 83, the Center for Medicare Advocacy helped Ms. B remain in her home despite the chronic and progressive nature of her Multiple Sclerosis. While she was denied coverage on numerous occasions, repeated appeals granted her Medicare coverage so she could stay home with safe and effective care.
- Ms. P (CT) – Living with ALS, Ms. P was able to stay home with ongoing help from her family and Medicare-covered nursing, therapy, and home health aides. Because Medicare was continued after a federal court appeal, Ms. P remained at home until the last 3 months of her life, when she decided she needed SNF care to be safe.
- Ms. M (ME) – Injured in a farming accident in 1948, Ms. M required a wheelchair and had significant functional limitations. She was informed she did not qualify for Medicare home health coverage and had to enter a nursing home. After appeals and on-going advocacy, she was able to return to, and remain, home with home health care.
- Ms. Jimmo (VT) – Lead plaintiff in the federal class action “improvement standard” case, Glenda Jimmo was blind and had a right leg amputation due to complications from diabetes. She required a wheelchair, and received multiple home health care visits per week for various treatments for her complex condition, until she was told that the care had to end because she wasn't going to improve. After administrative appeals and court action, Ms. Jimmo was able to remain home with necessary Medicare-covered skilled and home health aide care.

Unfortunately, to continue necessary Medicare coverage, these beneficiaries, and individuals like them, require zealous advocacy from attorneys with Medicare expertise. This kind of effort should not be necessary – and is not widely available. While ongoing Medicare-covered home care is available under the law, in practice, its receipt is the exception rather than the rule. This is demonstrated by the following examples:

- Mr. T (OR) – An 84 year old beneficiary, Mr. T is enrolled in a Medicare Advantage (MA) plan. He lives with multiple chronic conditions, serious skin wounds, and lymphedema. He had been getting Medicare-covered home health care, but the MA plan denied continued coverage despite an on-going physician order for skilled nursing care. The denial was appealed and won at the second level of appeal. However, Mr. T was only informed of the decision by telephone; he was told the Medicare decision-maker no longer issues written decisions. Without written proof, the MA plan would not re-start home health services. Unable to pay for the nursing, Mr. T's wounds reopened and emergency medical care was required. Professional advocacy was required to recommence home health services.
- Ms. R (TX) – Ms. R has Multiple Sclerosis and has been homebound for 12 years. Her MA plan has repeatedly informed her that it plans to discontinue her home health care, including skilled nursing, physical therapy, and aides. Only when Ms. R says she is appealing does it reinstate care. The plan has urged the beneficiary's physician to change his home health orders; he has not. Nonetheless, until advocates intervened, Ms. R's nursing and home health aides were discontinued.

Enforcing existing Medicare law and realizing the home care coverage that is currently allowed will help innumerable beneficiaries and caregivers. While this would not benefit all people who need in-home care, it would be a significant step towards filling an important gap in care, relieving the burden on family caregivers, and upholding the promise of Medicare.

2. Provide a Stand Alone Home Health Aide Benefit in Traditional Medicare

Congress should pass a focused, stand-alone home health aide benefit in traditional Medicare, to provide coverage for hands-on personal care without a homebound or skilled care requirement. As discussed above, a similar, albeit limited and discretionary benefit, was recently allowed in Medicare Advantage plans.⁶⁰

A stand-alone home health aide benefit could use the current Medicare definition of home health aide services. According to that definition, home health aide care would be “personal hands on care,” to include services that are enumerated in great detail in federal regulations.⁶¹ Threshold qualifying criteria could include, for example, that the individual has significant cognitive or mental health impairments, or is dependent in a defined number of activities of daily living (ADLs) or independent activities of daily living (IDLs). Eligibility would not be predicated on the individual being homebound or needing skilled nursing or therapy. As a consequence, this would provide home health aide coverage for beneficiaries who do not qualify under the current Medicare home health benefit.

Qualifying individuals could receive up to a certain number of hours of home health aide services per week, so long as they meet criteria. For example, coverage could be up to 28 – 35 hours per week, as in current law,⁶² or another eligibility metric could be mandated, based on a study of the population’s needs.

There have been other proposals to add an in-home care benefit through existing types of insurance associated with Medicare, such as Medicare supplemental insurance policies (known as Medigap), and Medicare Advantage (MA) plans.⁶³ We urge caution to this approach since it would not be universal, would further fragment and privatize Medicare, and would only be available to those who are able to pay additional premiums.

3. Opportunities for Further Exploration

There are many ideas and proposals that could be pursued through Medicare or other means to assist beneficiaries and family caregivers with in-home care. Some of these options include, but are not limited to, the following:

a. Comprehensive Benefit

Given the profound need for more coverage of long-term services and supports (LTSS), including in-home care and relief for caregivers, there have been many proposals to improve upon and expand our piecemeal, patchwork system of long-term care coverage. Such proposals have included incremental reforms as well as a full-fledged, comprehensive LTSS program.⁶⁴ Enacting legislation to create a LTSS benefit would certainly offer a solution for Medicare beneficiaries and their caregivers.

While there have been many proposals to create a comprehensive LTSS benefit, the Long Term Care Commission Alternative Report⁶⁵ outlined an approach in Medicare to create a viable long-term care system and financing solution. The Report recommended creating a “public social insurance program that is easily understood and navigated” that would “spread the risk for the costs of long-term services and supports as broadly as possible, provide benefits to people of all ages who need them, and allow individuals and families to meet their responsibilities.” One option would be to include a comprehensive LTSS benefit in Medicare Part A, which “has the advantage of relying on a system that is already in place and has history of adapting to changes in its benefit and financing structure.”

The Commissioners recognized that: “Importantly, since not all people with LTSS needs are eligible for Medicare, consideration should be given to including those who meet the agreed upon benefit criteria, but who would otherwise not be part of the Medicare program. In the alternative, other social insurance funding should be developed to meet these individuals’ needs.”

A comprehensive LTSS benefit is an important goal, but requires more commitment than is likely in the near future. Nonetheless, an analysis of possible solutions to assisting individuals and caregivers with longer-term care needs requires attention to this goal.

b. Incorporate a “Consumer-Directed” Care Model into Medicare, Similar to Medicaid

Regardless of whether assessing Medicare’s current home health benefit, or the potential addition of a focused or comprehensive benefit in the future, one area of exploration could be whether and to what extent Medicare should mirror certain aspects of Medicaid’s Home and Community Based Services (HCBS). As noted by PHI, a direct care worker advocacy organization, “consumer directed” in home care through HCBS is growing in relation to more traditional delivery models.⁶⁶ Under Medicare’s agency-based model, beneficiaries access the services they need through home care agencies, which handle all aspects of home care workers’ employment and deployment. In contrast, a consumer-directed model positions the individual as the locus of control over the care they need, with responsibility over most aspects of home care worker employment and schedules.

Unlike the consumer-directed care in Medicaid, Medicare home health coverage provides little role for beneficiaries to direct their own care. Home health aides are employed by an agency, rather than by the person receiving care; they generally arrive according to the agency’s schedule, not the individual’s. There is not a designated direct care worker to provide ongoing care to only one individual (or one household) over time. Instead, a rotating cast of aides come to a person’s home to provide whatever services are authorized by a given home health agency.

c. Medicare Respite Benefit

Adding a Medicare respite benefit for family caregivers is another limited, but valuable approach, that might be more feasible in the short term. As referenced above, some respite coverage is currently only available for terminally ill beneficiaries who elect the Medicare hospice benefit. Interestingly, however, Medicare did offer a broader respite benefit for a little over a year. Among other things, the Medicare Catastrophic Coverage Act of 1988 (MCCA) (Public Law 100-360) added respite care to the home health benefit, but was repealed in 1989 for other reasons.⁶⁷

In 2017, the Bipartisan Policy Center (BPC) outlined a Medicare respite benefit proposal that would be available to individuals who “have two or more ADL limitations or severe cognitive impairment; and must either: (1) have a primary, unpaid caregiver that resides with the beneficiary; or (2) qualify as an adult in need of emergency placement because of concerns that they are the victim of abuse.”⁶⁸ Eligible beneficiaries “would either need to: (1) be enrolled in an MA plan or an accountable care organization (ACO), or (2) be receiving chronic care management (CCM) services from a Medicare FFS [fee-for-service] clinician.”

d. Medicare Coverage Updates that Would Help Beneficiaries and Family Caregivers

There are adjustments to the Medicare program that Congress could pass to help beneficiaries and family caregivers. As noted in the LTC Commission’s Alternate Report, “[t]o meet the needs of those who qualify for Medicare, the current Medicare program must be adapted to reduce counterproductive, outdated and unreasonable barriers to outpatient therapies, home health and skilled nursing facility care.”⁶⁹ Among the recommendations made in the Report are:

- Revise the homebound requirement for Medicare home health coverage so that people who cannot obtain the services they need outside the home can obtain them at home;

- Remove the 3-day prior inpatient hospital stay requirement for skilled nursing facility (SNF) coverage, so that beneficiaries who do not need hospital care can qualify for Medicare SNF coverage; and
- Eliminate hospital “observation status,” or, at a minimum, count all days spent in the hospital as “inpatient” for purposes of qualifying for Medicare coverage for subsequent medically necessary SNF stays.

e. CMMI Demonstrations and Quality Payment Program

Authorized by the Affordable Care Act (ACA), the Center for Medicare and Medicaid Innovation (CMMI), managed by CMS, is tasked by Congress to “test models that improve care, lower costs, and better align payment systems to support patient-centered practices” in the Medicare, Medicaid, and Children’s Health Insurance Program (CHIP).⁷⁰ According to Section 3021 of ACA, CMMI was created to examine “innovative payment and service delivery models to reduce program expenditures ...while preserving or enhancing the quality of care”.

CMMI has significant flexibility to waive provisions of Medicare law in testing a demonstration, as well as the authority to ramp up models nationwide, if a model either reduces spending without reducing the quality of care, or improves the quality of care without increasing spending.⁷¹ As noted on its website, CMMI also plays a critical role in implementing the Quality Payment Program whereby “clinicians may earn incentive payments by participating to a sufficient extent in Advanced Alternative Payment Models (APMs).”⁷²

CMMI could use its authority and flexibility to test approaches for assisting family caregivers through the Medicare program and other mechanisms. This could include utilizing some of the elements of CMMI demonstrations and Quality Payment Program initiatives already underway, such as bundled payment models and medical home models. The following are some of the programs or initiatives that could be assessed for potentially adding payment models for family caregivers:

- *Independence at Home Demonstration* which provides chronically ill individuals with a range of primary care services in the home setting;⁷³
- *Primary Care First Initiative* starting in 2021 is a voluntary, alternative payment model aimed at reducing Medicare spending “by preventing avoidable inpatient hospital admissions, and improve quality and access to care for all beneficiaries, particularly those with complex chronic conditions and serious illness”;⁷⁴
- *Chronic Care Management Services (CCM)* - Since 2015, Medicare has been paying separately under the Medicare Physician Fee Schedule (PFS) for CCM services furnished to Medicare patients with multiple chronic conditions;⁷⁵ and
- *Transition Care Management (TCM) Services* – aimed at providing care coordination following discharge from a hospital or skilled nursing facility, including one face-to-face visit within specified timeframes, in combination with non-face-to-face services that may be performed by the physician or other qualified health care professional.⁷⁶

f. Lessons Learned from COVID-19

At the time of this writing, the United States and world are in the midst of the COVID-19 pandemic. In response, there have been many temporary waivers of existing rules in the Medicare program. Some of the waivers expand beneficiary coverage and rights and should be made permanent; some need further review; others should be rescinded as soon as possible.

The precipitous expansion of telehealth during the COVID crisis is one area to carefully consider. Telehealth brings promise for expanding access to some kinds of health care for some beneficiaries. However, it could also diminish access to best practices and personalized care. On the one hand, more people are able to contact their providers without visiting a physical office; on the other hand, such visits should be additive, not a substitute for needed in-person care. The availability of telehealth has already been allowed to weaken network adequacy standards in Medicare Advantage plans.⁷⁷ Furthermore, existing health disparities could be exacerbated by a move to more telehealth without careful study and planning.

With regard to in-home care, telehealth services can serve to support patients and family caregivers. However, it's worth remembering that home health aides are defined as providing personal, hands-on care. Patients and caregivers need human interaction and the innumerable benefits, planned and unplanned, that come with it. Telehealth should be additive – providing real time and urgent support, but it shouldn't supplant in-home human help.

There will be myriad lessons to learn from the pandemic. Some of these lessons will not be discernible until the crisis is over.

Conclusion

Medicare home health coverage is not being implemented to the full extent of the law. If it were, countless beneficiaries and families would be better off. Nonetheless, at best, the current Medicare benefit leaves far too many patients and caregivers behind. In order to provide quality home-based care for individuals, and support for their caregivers, significant changes are needed to the Medicare program and the broader health insurance system.⁷⁸

Endnotes

- ¹ Centers for Medicare & Medicaid Services (CMS) Data Snapshot on website at: <https://www.cms.gov/research-statistics-data-systems/preliminary-medicare-covid-19-data-snapshot>.
- ² “Beneficiaries/beneficiary” refers to people who are enrolled in Medicare. Generally these are individuals who are 65 or older who have earned sufficient Social Security or Railroad Retirement credits, and younger people with significant disabilities who have received Social Security Disability benefits for 24 months.
- ³ Commonwealth Fund, “Medicare: 50 Years of Ensuring Coverage and Care” (April 2015), available at: https://www.commonwealthfund.org/sites/default/files/documents/media_files_publications_fund_report_2015_apr_1812_davis_medicare_50_years_coverage_care.pdf.
- ⁴ See, e.g., U.S. Census Bureau website, “Who Are the Uninsured?” (Sept. 2018) available at: <https://www.census.gov/library/stories/2018/09/who-are-the-uninsured.html>; “only a small fraction of the uninsured — just 1.4 percent — were age 65 and over.”
- ⁵ Medicare Payment Advisory Commission (MedPAC), “Report to Congress: Medicare Payment Policy” (March 2019), Ch. 9, pp. 234-235, available at: http://www.medpac.gov/docs/default-source/reports/mar19_medpac_ch9_sec_rev.pdf?sfvrsn=0.
- ⁶ 42 U.S.C. §1395f(a)(2)(C); 42 C.F.R. §§409.42 et seq.
- ⁷ See, e.g., Centers for Medicare & Medicaid Services (CMS), Medicare Benefit Policy Manual, Chapter 9 - Coverage of Hospice Services Under Hospital Insurance, §40, et seq., available at: <https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/bp102c09.pdf>; also see 42 CFR §418.76 (aide and homemaker services) and 42 CFR §§418.108(b), 204(b) (respite care).
- ⁸ *The Hill*, “Family Caregivers Need Support, Medicare Should Cover In-Home Aides” by Laurie Archbald-Pannone, MD (November 15, 2019), available at: <https://thehill.com/opinion/healthcare/470677-family-caregivers-need-support-medicare-should-cover-in-home-care-aides>.
- ⁹ Kaiser Family Foundation, “Medicare Beneficiaries’ Financial Security Before the Coronavirus Pandemic” (April 2020), available at: <https://www.kff.org/medicare/issue-brief/medicare-beneficiaries-financial-security-before-the-coronavirus-pandemic/>.
- ¹⁰ See, Kaiser Family Foundation, “Medicare Beneficiaries’ Financial Security Before the Coronavirus Pandemic” (April 2020), available at: <https://www.kff.org/medicare/issue-brief/medicare-beneficiaries-financial-security-before-the-coronavirus-pandemic/>; “Problems Getting Care Due to Cost or Paying Medical Bills Among Medicare Beneficiaries” (April 2020), available at: <https://www.kff.org/coronavirus-covid-19/issue-brief/problems-getting-care-due-to-cost-or-paying-medical-bills-among-medicare-beneficiaries/>.
- ¹¹ 42 C.F.R. §408.48(a)-(b); MBP Manual, Ch. 7, §§401.1 and 70.1. See, *Jimmo v. Sebelius*, No. 11-cv-17 (D.Vt.), filed January 18, 2011; Settlement 2013; Corrective Action Plan 2017. See, <https://medicareadvocacy.org/medicare-info/improvement-standard/>. See, <https://www.cms.gov/Center/Special-Topic/Jimmo-Center>.
- ¹² For a fuller discussion of Medicare home health coverage, see, Chiplin Jr., Alfred, Stein, Judith, *Medicare Handbook*, Chapter 4, Home Health Coverage, (Wolters Kluwer, 2020; updated annually).
- ¹³ 42 U.S.C. §1395f(a)(2)(C); 42 C.F.R. §§409.42 et seq.
- ¹⁴ 42 U.S.C. §1395x(m).
- ¹⁵ 42 U.S.C. §1395x(m)(1)-(4).
- ¹⁶ 42 C.F.R. §409.42.
- ¹⁷ 42 C.F.R. §409.44.
- ¹⁸ Occupational therapy services can be either a qualifying service or a dependent service. Occupational therapy services that are not qualifying services under 42 C.F.R. §409.44(c) can be covered as dependent services if the requirements of reasonableness and necessity are met. 42 C.F.R. §409.45.
- ¹⁹ 42 C.F.R. §409.45.
- ²⁰ 42 C.F.R. §409.42(c)(4); Medicare Beneficiary Policy Manual, Ch. 7, §30.4.
- ²¹ 42 C.F.R. §§409.45(a)-(b).
- ²² 42 C.F.R. §409.41(a).
- ²³ 42 C.F.R. §409.45(b)(4).
- ²⁴ 42 C.F.R. §§409.48(a)-(b); Medicare Beneficiary Policy Manual, Ch. 7, §§40,1.1 and 70.1.
- ²⁵ *Health Affairs*, “Financial Hardships of Medicare Beneficiaries With Serious Illness” by Kyle, Blendon, et al, Vol. 38, No. 11, pp. 1801-1806 (November 2019). Note: The authors define “serious illness” as individuals “reported having a serious illness or condition that, over the past three years, had required two or more hospital stays and visits to three or more physicians.” p. 1802

²⁶ *The Hill*, “Family Caregivers Need Support, Medicare Should Cover In-Home Aides” by Laurie Archbald-Pannone, MD (November 15, 2019), available at: <https://thehill.com/opinion/healthcare/470677-family-caregivers-need-support-medicare-should-cover-in-home-care-aides>.

²⁷ 42 U.S.C. §1395x(m)(1)-(4). Note, receipt of skilled therapy can also trigger coverage for home health aides.

²⁸ 42 CFR §409.45(b)(1)(i)-(v). See also, Medicare Benefits Policy Manual, Chapter 7, §§50.1 and 50.2.

²⁹ Medicare Payment Advisory Commission (MedPAC), “Report to Congress: Medicare Payment Policy” (March 2019), Ch. 9, pp. 234-235, available at: http://www.medpac.gov/docs/default-source/reports/mar19_medpac_ch9_sec_rev.pdf?sfvrsn=0.

³⁰ *Kaiser Health News*, “Seniors Aging In Place Turn To Devices And Helpers, But Unmet Needs Are Common” by Judith Graham (February 14, 2019), available at: <https://khn.org/news/seniors-aging-in-place-turn-to-devices-and-helpers-but-unmet-needs-are-common/>.

³¹ See also, Johns Hopkins University Bloomberg School of Public Health study that also finds people with limitations in activities of daily living (ADLs) experience significant harm when they cannot access adequate help with ADLs at home. “Medicare Spending and the Adequacy of Support with Daily Activities in Community-Living Older Adults with Disability” by Jennifer L. Wolff, Lauren H. Nicholas, Amber Willink, John Mulcahy, Karen Davis and Judith D. Kasper, Commonwealth Fund and National Institutes on Aging (May 2019), as reported by American Association for the Advancement of Science (AAAS) EurekAlert website at: https://www.eurekalert.org/pub_releases/2019-05/jhbmsh_1052819.php.

³² *The Hill*, “Family Caregivers Need Support, Medicare Should Cover In-Home Aides” by Laurie Archbald-Pannone, MD (November 15, 2019), available at: <https://thehill.com/opinion/healthcare/470677-family-caregivers-need-support-medicare-should-cover-in-home-care-aides>.

³³ Centers for Medicare & Medicaid Services (CMS), Medicare-Medicaid Coordination Office, Fact Sheet: “People Dually Eligible for Medicare and Medicaid” (March 2020), available at: https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/Downloads/MMCO_Factsheet.pdf.

³⁴ *Health Affairs*, “Financial Hardships of Medicare Beneficiaries With Serious Illness” by Kyle, Blendon, et al, Vol. 38, No. 11, pp. 1801-1806 (November 2019).

³⁵ 42 C.F.R. §409.45(b)(2)(iii)

³⁶ CMS, Medicare Benefit Policy Manual, Ch. 7, Sec. 20.2, “Impact of Other Available Caregivers and Other Available Coverage on Medicare Coverage of Home Health Services” (updated April 22, 2015).

³⁷ See, Center for Medicare Advocacy “Home Health Practice Guide: Medicare Home Health Coverage and Care Is Jeopardized By the New Payment Model – The Center for Medicare Advocacy May Be Able to Help” (Jan. 7, 2020) available at: <https://medicareadvocacy.org/home-health-practice-guide/>; also see, e.g., Center for Medicare Advocacy Weekly Alert “Medicare Coverage of Home Health Care Has Not Changed Under the New Payment System (PDGM)” (Feb. 20, 2020), available at: <https://medicareadvocacy.org/medicare-coverage-of-home-health-care-has-not-changed-under-the-new-payment-system-pdgm/>.

³⁸ *Home Health Care News*, “CMS Watching Home Health Providers Closely Amid Shifting Therapy Strategies” by Robert Holly, (Feb. 12, 2020), available at: <https://homehealthcarenews.com/2020/02/cms-watching-home-health-providers-closely-amid-shifting-therapy-strategies/>.

³⁹ CMS, MLN Matters article “The Role of Therapy under the Home Health Patient-Driven Groupings Model (PDGM)”, Number: SE20005 (Feb. 10, 2020), available at: <https://www.cms.gov/files/document/se20005.pdf>.

⁴⁰ 42 U.S.C. §1395w-22(a); 42 C.F.R. §422.101. Note that MA plans do not have to cover hospice services.

⁴¹ See, e.g., Medicare Payment Advisory Commission (MedPAC), “Medicare Advantage Program Payment System” (October 2018), available at: http://www.medpac.gov/docs/default-source/payment-basics/medpac_payment_basics_18_ma_final_sec.pdf?sfvrsn=0.

⁴² As noted by the Urban Institute, in the MA program, “supplemental benefits are used to attract enrollees and can confer a competitive advantage.” Urban Institute, “Are Medicare Advantage Plans Using New Supplemental Benefit Flexibility to Address Enrollees’ Health-Related Social Needs?” (Sept. 2019), available at: https://www.urban.org/sites/default/files/publication/101067/sdh_medicare_advantage.pdf.

⁴³ See, e.g., Health Management Associates, “Medicare Advantage Supplemental Benefit Flexibilities: Adoption of and Access to Newly Expanded Supplemental Benefits in 2020” (May 2020), available at: https://www.healthmanagement.com/wp-content/uploads/Medicare_Advantage_Supplemental_Benefit_Flexibilities_Issue_Brief_2-27-20_HMA.pdf.

⁴⁴ D-SNPs can provide “flexible supplemental benefits” including some in-home non-skilled support services, as well as support for caregivers (respite, counseling and training); see, e.g., CMS, Medicare Managed Care Manual, Chapter 16B: Special Needs Plans, Table 3 – p. 21, available at: <https://www.cms.gov/Regulations-and->

[Guidance/Guidance/Manuals/Downloads/mc86c16b.pdf](#). Access to such services is contingent upon being dually eligible for Medicare and Medicaid, living in a geographic area where a D-SNP is offered, and such D-SNP choosing to offer these types of services. As noted by the Urban Institute, “most of the work to address social needs [in the Medicare program] has focused on limited demonstrations and private plans covering those dually eligible for Medicare and Medicaid [D-SNPs]. Though this approach generally targets lower-income Medicare beneficiaries, the narrow focus on dual eligibles may exclude beneficiaries whose health-related social needs are less directly tied to income, as well as beneficiaries eligible for supplemental Medicaid coverage but unenrolled” [citations omitted]. Urban Institute, “Are Medicare Advantage Plans Using New Supplemental Benefit Flexibility to Address Enrollees’ Health-Related Social Needs?” (Sept. 2019), available at:

https://www.urban.org/sites/default/files/publication/101067/sdh_medicare_advantage.pdf.

⁴⁵ CMS memo to MA plan sponsors entitled “Reinterpretation of Primarily Health Related’ for Supplemental Benefits” (April 27, 2018), available at:

<https://www.dropbox.com/s/pee7o4igqye12ts/HPMS%20Memo%20Primarily%20Health%20Related%204-27-18.pdf?dl=0>.

⁴⁶ *Id.*

⁴⁷ *Home Health Care News*, “Why Home Care Can Still Define Medicare Advantage in 2020” by Robert Holly (January 14, 2020), available at: <https://homehealthcarenews.com/2020/01/why-home-care-can-still-define-medicare-advantage-in-2020/>.

⁴⁸ Health Management Associates, “Medicare Advantage Supplemental Benefit Flexibilities: Adoption of and Access to Newly Expanded Supplemental Benefits in 2020” (May 2020), available at:

https://www.healthmanagement.com/wp-content/uploads/Medicare_Advantage_Supplemental_Benefit_Flexibilities_Issue_Brief_2-27-20_HMA.pdf.

⁴⁹ In a 2019 report, the Urban institute interviewed various stakeholders about the new benefit flexibilities: “Insurers discussed several trade-offs in the decision to add a benefit, many of which closely related to costs. For example, insurers noted that adding new supplemental benefits often requires reducing a current supplemental benefit to free up funding. Insurers were particularly hesitant to remove benefits consumers were already familiar with because such changes may affect member satisfaction scores. In turn, this could influence their star ratings, which would affect the rebate amount available to fund new benefits.” Further, these stakeholder interviews highlighted “plans’ concerns about investing in benefits that reach a small number of enrollees and therefore have limited appeal to a broad group of beneficiaries.” Urban Institute, “Are Medicare Advantage Plans Using New Supplemental Benefit Flexibility to Address Enrollees’ Health-Related Social Needs?” (Sept. 2019), available at:

https://www.urban.org/sites/default/files/publication/101067/sdh_medicare_advantage.pdf.

⁵⁰ Urban Institute, “Are Medicare Advantage Plans Using New Supplemental Benefit Flexibility to Address Enrollees’ Health-Related Social Needs?” (Sept. 2019), available at:

https://www.urban.org/sites/default/files/publication/101067/sdh_medicare_advantage.pdf. Similarly, as noted by Health Management Associates, “[t]he vast majority of individuals enrolled in plans offering at least one new supplemental benefit are enrolled in plans with star ratings of four stars or above [which entitle plans to bonus payments], raising the question whether the availability of additional rebate dollars factored into a plan’s determination to offer these benefits.” Health Management Associates, “Medicare Advantage Supplemental Benefit Flexibilities: Adoption of and Access to Newly Expanded Supplemental Benefits in 2020” (May 2020), available at: https://www.healthmanagement.com/wp-content/uploads/Medicare_Advantage_Supplemental_Benefit_Flexibilities_Issue_Brief_2-27-20_HMA.pdf.

⁵¹ Urban Institute, “Are Medicare Advantage Plans Using New Supplemental Benefit Flexibility to Address Enrollees’ Health-Related Social Needs?” (Sept. 2019), available at:

https://www.urban.org/sites/default/files/publication/101067/sdh_medicare_advantage.pdf. Also see, e.g., Center for Medicare Advocacy Issue Brief: “New Medicare Advantage Supplemental Benefits: An Advocates’ Guide to Navigating the New Landscape” (October 2019) available at: <https://www.medicareadvocacy.org/wp-content/uploads/2019/10/Fully-Informed-Advocates-Guide-to-MA-Supplemental-Benefits-2019.pdf>.

⁵² See, e.g., various Center for Medicare Advocacy Weekly Alerts and citations therein, including “Medicare Trustees Report: Projections Similar to Last Year, and Savings Are Available” (April 30, 2020), available at: <https://medicareadvocacy.org/medicare-trustees-report-projections-similar-to-last-year-and-savings-are-available/>; “Medicare Advantage Continues to Drive Up Medicare Costs – Congress Must Act to Level the Playing Field with Traditional Medicare” (February 4, 2020), available at: <https://medicareadvocacy.org/medicare-advantage-continues-to-drive-up-medicare-costs/>; “Government Watchdog Agency Once Again Finds Wasteful Medicare Advantage Overpayment” (December 20, 2019), available at: <https://medicareadvocacy.org/government-watchdog-agency-once-again-finds-wasteful-medicare-advantage-payment/>; and “Support Traditional Medicare by Leveling

the Playing Field with Medicare Advantage” (August 15, 2019), available at: <https://medicareadvocacy.org/support-traditional-medicare-by-leveling-the-playing-field-with-medicare-advantage/>.

⁵³ As noted by the Urban Institute, these new supplemental benefits “will not be available to traditional Medicare enrollees, leading to concerns about equity in benefits and outcomes across the Medicare program.” Urban Institute, “Are Medicare Advantage Plans Using New Supplemental Benefit Flexibility to Address Enrollees’ Health-Related Social Needs?” (Sept. 2019), available at:

https://www.urban.org/sites/default/files/publication/101067/sdh_medicare_advantage.pdf.

⁵⁴ Kaiser Family Foundation, “A Dozen Facts About Medicare Advantage in 2020” (April 2020), available at:

<https://www.kff.org/medicare/issue-brief/a-dozen-facts-about-medicare-advantage-in-2020/>.

⁵⁵ The Commission was created pursuant to the American Taxpayer Relief Act of 2012, Pub. Law 112-240, Section 643; the text of the bill is available at: <http://www.gpo.gov/fdsys/pkg/BILLS-112hr8eas/pdf/BILLS-112hr8eas.pdf>.

⁵⁶ LTC Commission – Alternative Report and Recommendations (Sept. 2013), available at:

<https://www.medicareadvocacy.org/wp-content/uploads/2013/10/LTCCAlternativeReport.pdf>.

⁵⁷ See Center for Medicare Advocacy Issue Brief “Plans to Address and Resolve the Medicare Home Care Crisis” (Oct. 2018), available at: <https://medicareadvocacy.org/plans-to-address-and-resolve-the-medicare-home-care-crisis/>.

⁵⁸ CMS MLN Article, “The Role of Therapy under the Home Health Patient-Driven Groupings Model (PDGM)” (Feb. 10, 2020), available at: <https://www.cms.gov/files/document/se20005.pdf>.

⁵⁹ Note that some of these stories are available on the Center for Medicare Advocacy’s website; some clients’ names are used there with their permission. See, e.g., <https://medicareadvocacy.org/why-the-jimmo-v-sebelius-case-matters-improvement-standard-stories/>; <https://medicareadvocacy.org/voices-of-medicare/>; and <https://medicareadvocacy.org/the-2015-national-voices-of-medicare-summit/>.

⁶⁰ See Center for Medicare Advocacy CMA Alert “Home Health Aide Coverage Continues to Shrink in Traditional Medicare While CMS Enhances it in Medicare Advantage” (Nov. 15, 2018), available at:

<https://medicareadvocacy.org/home-health-aide-coverage-continues-to-shrink-in-traditional-medicare-while-cms-enhances-it-in-medicare-advantage/>.

⁶¹ See 42 C.F.R. §409.45(b)(1)-(4).

⁶² Note that there is precedent for this recommendation. For example, people can get physical therapy, occupational therapy, and speech language pathology as part of the overall Medicare home health benefit if they meet coverage criteria; but they can also get this therapy under Part B if they do not qualify for home health coverage. Further, some supplies are covered under the overall home health benefit, but Durable Medical Equipment is covered as a separate Part B benefit.

⁶³ For example, in 2017 the Bipartisan Policy Center (BPC) issued a report proposing, among other things, to add a limited LTSS benefit to Medigap policies and to MA plans that “would provide reimbursement for provision of home-based services similar to the level of services covered in the existing LTCI market, including services provided in the home by a licensed medical practitioner or home care aide, as well as other services to help individuals remain in their homes.” BPC’s proposal would be voluntary in that CMS “would amend Medigap and MA requirements to permit plans to offer existing benefits along with a new limited LTSS benefit, which beneficiaries could elect to enroll in, and pay corresponding premiums to cover the cost of the benefit.” Bipartisan Policy Center (BPC) report “Financing Long-Term Services and Supports: Seeking Bipartisan Solutions in Politically Challenging Times” (July 2017), available at:

<https://bipartisanpolicy.org/wp-content/uploads/2019/03/BPC-Health-Financing-Long-Term-Services-and-Supports.pdf>.

⁶⁴ There is voluminous research on this topic; for a recent publication, see, e.g., Urban Institute research paper “Incorporating Long-Term Services and Supports in Health Care Proposals - Cost and Distributional Considerations” (May 2020), available at:

https://www.urban.org/research/publication/incorporating-long-term-services-and-supports-health-care-proposals/view/full_report.

⁶⁵ LTC Commission – Alternative Report and Recommendations (Sept 2013), available at:

<https://www.medicareadvocacy.org/wp-content/uploads/2013/10/LTCCAlternativeReport.pdf>; note that the comprehensive Part A LTSS benefit is outlined at pp. 6-8.

⁶⁶ PHI (Paraprofessional Healthcare Institute) report, “We Can Do Better: How Our Broken Long-Term Care System Undermines Care” (April 2020), available at: <https://phinational.org/wp-content/uploads/2020/04/We-Can-Do-Better-2020-PHI.pdf>.

⁶⁷ See, e.g., U.S. General Accounting Office (GAO), “MEDICARE CATASTROPHIC ACT - Options for Changing Financing and Benefits” (Sept. 1989), available at: <https://www.gao.gov/assets/220/211638.pdf>; also see, e.g.,

Boise, Linda, “The Demise of the Catastrophic Coverage Act: A Reflection of the Inability of Congress to Respond to Changing Needs of the Elderly and their Families” (June 1990), *The Journal of Sociology & Social Welfare*, Vol. 17, Issue 2, available at:

<https://scholarworks.wmich.edu/cgi/viewcontent.cgi?article=1942&context=jssw>.

⁶⁸ Bipartisan Policy Center (BPC) report, “Financing Long-Term Services and Supports: Seeking Bipartisan Solutions in Politically Challenging Times” (July 2017), available at:

<https://bipartisanpolicy.org/wp-content/uploads/2019/03/BPC-Health-Financing-Long-Term-Services-and-Supports.pdf>.

⁶⁹ LTC Commission – Alternative Report and Recommendations (Sept 2013), available at:

<https://www.medicareadvocacy.org/wp-content/uploads/2013/10/LTCCAAlternativeReport.pdf>; see pp. 13-14; also see, e.g., the Center for Medicare Advocacy’s “Medicare Platform: Core Considerations for Today & Tomorrow” (updated Jan. 2019), available at <https://medicareadvocacy.org/core-considerations-for-medicare-for-today-tomorrow-a-medicare-platform-for-the-new-congress/>.

⁷⁰ See the CMMI website at: <https://innovation.cms.gov/about>; also see, e.g., Kaiser Family Foundation Fact Sheet: “What is CMMI? And 11 Other FAQs about the CMS Innovation Center” (February 2018), available at:

<http://files.kff.org/attachment/Fact-Sheet-What-is-CMMI-and-other-FAQs-about-the-Innovation-Center>.

⁷¹ CMMI website.

⁷² CMMI website; for more information about the Quality Payment Program, see CMS’ website at:

<https://qpp.cms.gov/>.

⁷³ See, e.g., CMMI website at: <https://innovation.cms.gov/innovation-models/independence-at-home>.

⁷⁴ CMS FAQ on Primary Care First Initiative: <https://innovation.cms.gov/files/x/pcf-faqs.pdf>; also see CMMI website at: <https://innovation.cms.gov/innovation-models/primary-care-first-model-options>.

⁷⁵ See, e.g., CMS MLN Booklet “Chronic Care Management Services” (July 2019), available at:

<https://www.cms.gov/outreach-and-education/medicare-learning-network-mln/mlnproducts/downloads/chroniccaremanagement.pdf>.

⁷⁶ See, e.g., outdated CMS MLN article on TCM from 2016: <https://www.nhpco.org/wp-content/uploads/2019/04/Transitional-Care-Management-Services-Fact-Sheet-ICN908628.pdf>; note that at time of publication, CMS is in the process of revising this MLN article (see <https://www.cms.gov/outreach-and-education/medicare-learning-network-mln/mlnproducts/downloads/transitional-care-management-services-fact-sheet-icn908628.pdf>); also see description of TCM services by Medicare contractor Noridian at:

<https://med.noridianmedicare.com/web/jeb/specialties/em/transitional-care-management-tcm>.

⁷⁷ See, e.g., Center for Medicare Advocacy comments to the Centers for Medicare & Medicaid Services’ (CMS) Interim Final Rule with Comment: Medicare and Medicaid Programs; Policy and Regulatory Revisions in Response to the COVID-19 Public Health Emergency (CMS-1744-IFC), at 85 Federal Register 19230 (April 6, 2020). See the Center’s comments, and citations, therein, here: <https://medicareadvocacy.org/center-comments-on-policy-and-regulatory-revisions-in-response-to-covid-19/>.

⁷⁸ This paper was authored by Judith A. Stein, Executive Director, and David A. Lipschutz, Associate Director, Center for Medicare Advocacy, with support from The John A. Hartford Foundation.