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# MEDICARE COVERAGE for INDIVIDUALS UNDER 65 with DISABILITIES

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## I. MEDICARE ELIGIBILITY

Generally, individuals who are 65 and are entitled to and receiving Social Security or Railroad Retirement benefits are automatically entitled to and enrolled in Medicare Part A and will be deemed to have also enrolled in Part B unless they opt out. Social Security Act, §206, 42 U.S.C. §1395p(f). Persons who are not yet receiving Social Security or Railroad Retirement benefits must enroll in Part A during an initial enrollment period, which begins in the third month before the person reaches age 65 (or reaches age 65 and becomes a U.S. citizen, or a permanent resident who has lived continually in the United States for the five years immediately preceding application for Medicare). The initial enrollment period extends for the next seven months. In addition, note that married individuals may be able to qualify for Medicare under their spouse's account. Since 2013, this includes spouses in legally recognized same-sex marriages. 42 U.S.C. §1395i-2(a); 42 C.F.R. §406.21(b).

SSDI and the 24-Month Waiting Period

Medicare is also available for certain people with disabilities who are under age 65. These individuals must have received Social Security Disability or Railroad Retirement disability benefits for 24 months. Since there is a five month waiting period after a beneficiary is determined to be disabled before a beneficiary begins to collect Social Security Disability benefits, the person actually becomes entitled to Medicare Part A after being disabled for 29 months. 42 USC §1395c; 42 CFR §406.12.

Months of a previous period of entitlement or deemed entitlement to disability benefits may count toward the 25-month requirement. 42 CFR §406.12(b). Also note that deemed entitlement to disabled widow's or widower's monthly benefits may be used to meet the 25-month requirement or to retain Part A entitlement when they are no longer entitled to monthly disability benefits. 42 CFR §406.12(c). *Also see* 42 CFR §406.6 re: who must apply for benefits.

As summarized in §10.3, Ch. 2, Medicare General Information, Eligibility and Entitlement Manual (CMS Pub. 100-01):

> [D]isabled persons who are not insured for monthly Social Security disability benefits but would be insured for such benefits if Government [quarters of coverage, or QCs] were treated as social security QCs, are deemed to be entitled to disability benefits and automatically entitled to [Part A] after being disabled for 29 months.
>
> The months in the Medicare qualifying period need not be consecutive so that months from a previous period of disability benefit entitlement generally may be counted in determining when the qualifying period requirement is met. [Part A] entitlement on the basis of disability is available not only to the worker, but to the widow, widower, or child of a deceased, disabled, or retired worker if any of them become disabled within the meaning of the Social Security or Railroad Retirement Acts.
>
> If an individual recovers from a disability, [Part A] entitlement ends with the month after the month he or she is notified of the disability termination. For example, if notification is November 15, entitlement ends December 31. However, if the individual's disability benefit entitlement ends only because he or she was working,[Part A] entitlement may continue for up to 78 additional months [note: see discussion below re: Eligibility for Working People with Disabilities].

Note that individuals who are receiving Social Security benefits cannot waive their entitlement to Medicare Part A. In order to waive Part A, they must withdraw their Social Security application and return any retirement or disability benefits they have received (but because Part B is voluntary, an individual may always decline Part B). Social Security Program Operations Manual System (POMS), §HI 00801.002; *Hall v. Sebelius*, 2011 WL 891818 (D.D.C. Mar. 16, 2011).

<u>Exceptions to the Waiting Period – ESRD and ALS</u>

Individuals with End Stage Renal Disease (ESRD) or Amyotrophic Lateral Sclerosis (ALS, also known as Lou Gehrig's disease), in contrast to persons with other causes of disability, do not have to collect benefits for 24 months in order to be eligible for Medicare.

ESRD

Individuals of any age with ESRD who receive dialysis on a regular basis or a kidney transplant are eligible for Part A (and are deemed enrolled for Part B unless such coverage is refused) if they file an application. "They must also meet certain work requirements for insured status under the social security or railroad retirement programs, or be entitled to monthly social security benefits or an annuity under the Railroad Retirement Act, or be the spouse or dependent child of an insured or entitled person." §10.4, Ch. 2, Medicare General Information, Eligibility and Entitlement Manual (CMS Pub. 100-01); *also see* 42 CFR §406.13(c).

"Entitlement usually begins after a 3-month waiting period has been served, i.e., with the first day of the third month after the month in which a course of regular dialysis begins. Entitlement begins before the waiting period has expired if the individual receives a transplant or participates in a self-dialysis training program during the waiting period." §10.4.1, Ch. 2, Medicare General Information, Eligibility and Entitlement Manual (CMS Pub. 100-01); see §§10.4.2 -.3 for more information concerning entitlement based upon transplant and self-dialysis.

Part A coverage based on ESRD ends with the earliest of the following dates:

- The day an individual dies,
- The last day of the 12th month after the month the course of dialysis is discontinued, unless the individual receives a kidney transplant during that period or begins another course of dialysis, or
- The last day of the 36th month after the month the person receives a kidney transplant.

§10.4.4, Ch. 2, Medicare General Information, Eligibility and Entitlement Manual (CMS Pub. 100-01); *also see* 42 CFR §406.13.

Note that there are a number of issues to consider regarding whether or not to enroll in Medicare is someone has ESRD; for a general overview, see, e.g., Medicare Coverage of Kidney Dialysis & Kidney Transplant Services (Centers for Medicare & Medicaid Services), available at: https://www.medicare.gov/Pubs/pdf/10128-Medicare-Coverage-ESRD.pdf.

ALS

Persons with ALS can qualify for Medicare immediately upon collecting Social Security Disability benefits, without the 24-month waiting period, effective July 1, 2001. Benefits Improvement and Protection Act (BIPA), Pub. L. 106-554 (December 21, 2000), §115.

## II. WORKING PEOPLE WITH DISABILITIES

There are distinct sets of rules in Medicare concerning: 1) how Medicare coordinates with other types of insurance, including employer-based insurance (Medicare Secondary Payer, or MSP); and 2) continuing eligibility for individuals with disabilities who are working. Each set of rules is addressed, in turn, below.

Medicare Secondary Payer (MSP)

The Medicare Secondary Payer (MSP) program is designed to reduce costs to the Medicare program by requiring other insurers of health care for beneficiaries to pay primary to Medicare. It applies in three situations: where there is liability insurance, e.g. for an accident; where there is workers compensation coverage, e.g., for a job related injury; and where there is an employer's large group health plan (EGHP). See 42 U.S.C. § 1395y(b); 42 C.F.R. §§ 411.20 et seq.

See, e.g., Center for Medicare Advocacy website at: http://www.medicareadvocacy.org/medicare-info/medicare-secondary-payer-program/

Large Group Health Plans (LGHPs)

The Medicare Secondary Payer Manual (CMS Pub. 100-05), Ch. 1, §10.3, states:

> Medicare benefits are secondary payer to "large group health plans" (LGHP) for individuals under age 65 entitled to Medicare on the basis of disability and whose LGHP coverage is based on the individual's current employment status or the current employment status of a family member. Under the law, a LGHP may not "take into account" that such an individual is eligible for, or receives, Medicare benefits based on disability. […]

Medicare benefits are secondary to benefits payable under a LGHP for individuals under age 65 entitled to Medicare on the basis of disability who are covered under a LGHP as a result of the:

- Individual's current employment status with an employer that has 100 employees or more (see chapter 2, §30.3); or
- Current employment status of a family member with such employer.

See, generally, 42 USC §1395y(b); 42 CFR §411.100, et seq., and 411.200, et seq..; Medicare Secondary Payer Manual (CMS Pub. 100-05), Ch. 2, §§10, et seq.

Rules for Individuals with ESRD

The Medicare Secondary Payer Manual (CMS Pub. 100-05), Ch. 1, §10.2, states

> Medicare benefits are secondary to benefits payable under a GHP [group health plan] for individuals eligible for or entitled to benefits on the basis of ESRD during a period of up to 30 months if Medicare was not the proper primary payer for the individual on the basis of age or disability at the time that this individual became eligible or entitled to Medicare on the basis of ESRD.
>
> The coordination period begins when the individual is eligible for Medicare. Medicare is secondary during this period even if the employer policy or plan contains a provision stating that its benefits are secondary to Medicare, or otherwise excludes or limits its payments to Medicare beneficiaries. Under this provision, the GHP is billed first for services provided to a Medicare ESRD beneficiary. If the GHP does not pay for covered services in full, Medicare may pay secondary benefits in accordance with current billing instructions. This provision applies to all Medicare covered items and services (not just treatment of ESRD) furnished to beneficiaries who are in the coordination period.

*See, generally*, 42 USC §1395y(b)(1)(C); 42 CFR §411.160, et seq., Medicare Secondary Payer Manual (CMS Pub. 100-05), Ch. 2, §§20, et seq.; *also see* CMS, Medicare Learning Network (MLN) article, "Medicare Secondary Payer" (April 2020), available at: https://www.cms.gov/outreach-and-education/medicare-learning-network-mln/mlnproducts/downloads/msp_fact_sheet.pdf.

Medicare Eligibility for Working People with Disabilities

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Medicare eligibility for working people with disabilities falls into three distinct time frames. The first is the trial work period, which extends for 9 months after a disabled individual obtains a job. The second is the seven-and-three-quarter years (93 months) after the end of the trial work period. Finally, there is an indefinite period following those 93 months. (See the statute at 42 U.S.C. § 422(c), and regulation at 20 C.F.R. § 404.1592; also see 42 CFR §406.12(e)). Keep in mind that Medicare eligibility during each of these periods applies only while the individual continues to meet the medical standard for being considered disabled under Social Security rules.

- **Trial Work Period (TWP)**

An individual who is receiving Social Security disability benefits is entitled to continue receiving Medicare as well as Social Security income during a maximum 9 month "trial work" period during any rolling 5 year time period. To qualify, an individual must have gross earnings of at least $910 per month in 2020 (see http://www.ssa.gov/oact/cola/twp.html), or work more than 80 hours of self-employment per month. The nine months of the trial work period do not necessarily have to be consecutive. During the trial work period, the ability to perform such work will not disqualify the individual from being considered disabled and receiving Social Security and Medicare benefits. However, independent evidence that the individual is no longer disabled could end benefits during the trial work period. After the nine month trial work period has ended, the work performed during it may be considered in determining whether the individual is no longer disabled, and thus no longer eligible for Social Security income and Medicare benefits.

- **Extended Period of Eligibility (EPE)**

Individuals who still have the disabling impairment but have earned income that meets or exceeds the "Substantial Gainful Activity" level can continue to receive Medicare health insurance after successfully completing a trial work period. The Substantial Gainful Activity level for 2020 is $1,260 a month, or $2,110 for the blind (see

http://www.socialsecurity.gov/oact/cola/sga.html). This new period of eligibility can continue for as long as 93 months after the trial work period has ended, for a total of eight-and-one-half years including the 9 month trial work period. During this time, though SSDI cash benefits may cease, the beneficiary pays no premium for the hospital insurance portion of Medicare (Part A). Premiums are due for the supplemental medical insurance portion (Part B). If the individual's employer has more than 100 employees, it is required to offer health insurance to individuals and spouses with disabilities, and Medicare will be the secondary payer. For smaller employers who offer health insurance to persons with disabilities, Medicare will remain the primary payer.

- **Indefinite Access to Medicare**

Even after the eight-and-one-half year period of extended Medicare coverage has ended, working individuals with disabilities can continue to receive benefits as long as the individual remains medically disabled. At this point the individual – who must be under age 65 – will have to pay the premium for Part A as well as the premium for Part B. The amount of the Part A premium will depend on the number of quarters of work in which the individual or his spouse have paid into Social Security. Individuals whose income is low, and who have resources under $4,000 ($6,000 for a couple), can get help with payment of these premiums under a state run buy-in program for Qualified Disabled and Working Individuals (QDWI).

The following information about the QDWI program is from the www.medicare.gov website at: http://www.medicare.gov/your-medicare-costs/help-paying-costs/medicare-savings-program/medicare-savings-programs.html#collapse-2625

QDWI income & resource limits in 2020:

Individual monthly income limit*

$4,339

Married couple monthly income limit*

$5,833

*Limits are slightly higher in Alaska and Hawaii. If you have income from working, you may qualify for benefits even if your income is higher than the limits listed.

Individual resource limit

$4,000

Married couple resource limit

$6,000

Program helps pay for:

Part A premiums only

## III. WAYS to SUPPLEMENT MEDICARE

Overview

Medicare has four parts: Part A, Part B, Part C, and Part D. Part A covers inpatient hospital care, inpatient care in a skilled nursing facility (SNF), home health care services, and hospice care. 42 U.S.C. §§ 1395c and 1395d. Part B covers medical care and services provided by physicians and other medical practitioners, durable medical equipment (DME), hospital "observation" stays, a variety of outpatient care services, preventive services, and home health services not otherwise covered under Part A. 42 U.S.C. §§ 1395j and 1395k.

Medicare Part C, or Medicare Advantage (MA), includes a variety of private plan options for the *financing* of Medicare-covered health services. These MA options must offer the core package of benefits available under Parts A and B, plus additional benefits. 42 U.S.C. §§ 1395w-21 *et seq.*

In 2006, Medicare Part D added a prescription drug benefit offered through private insurance plans. Part D only specifies the deductible, copayment, and out-of-pocket limits for the drug benefits. Within certain statutory requirements, Part D plans set their own drug formularies and premiums and may vary the cost-sharing as long as the overall cost-sharing is the "actuarial equivalent" of the statutory standard benefit. *See* MMA, adding §§ 1860D-1–1860D-42 of the Social Security Act, 42 U.S.C. §§ 1395w-101–1395w-151.

Medicare is neither cost-free nor is it comprehensive in coverage; Medicare requires deductibles and copayments and pays only a portion of the cost of certain services for certain patients. Thus, Most people have Medicare plus some other type of supplemental coverage to help fill in some

of these gaps.

According to the Kaiser Family Foundation (see "An Overview of Medicare" (Feb. 2019), available at: https://www.kff.org/medicare/issue-brief/an-overview-of-medicare/) different types of supplemental coverage in Medicare is distributed as follows:

- "In 2018, one-third of all beneficiaries were enrolled in Medicare Advantage plans rather than traditional Medicare, some of whom also have coverage from a former employer/union or Medicaid";
- Of those in traditional, or Original Medicare (as of 2016):
    - "Employer-sponsored insurance provided retiree health coverage to 3 in 10 (30%) of traditional Medicare beneficiaries"
    - "Medigap, also called Medicare supplement insurance, provided supplemental coverage to nearly 3 in 10 (29%) beneficiaries in traditional Medicare"
    - "Medicaid, the federal-state program that provides coverage to low-income people, was a source of supplemental coverage for more than 1 in 5 (22%, or 7.0 million) traditional Medicare beneficiaries with low incomes and modest assets in 2016 (not including 3.5 million beneficiaries who were enrolled in both Medicare Advantage and Medicaid). These beneficiaries are known as dually eligible beneficiaries because they are eligible for both Medicare and Medicaid. Most traditional Medicare beneficiaries who receive Medicaid (5.3 million) receive both full Medicaid benefits, including long-term services and supports, and payment of their Medicare premiums and cost sharing. Another 1.7 million beneficiaries do not qualify for full Medicaid benefits but Medicaid covers their Medicare premiums and/or cost sharing through the Medicare Savings Programs."
    - "Nearly 1 in 5 (19%, or 6 million) Medicare beneficiaries with traditional Medicare had no supplemental coverage in 2016. These 6 million beneficiaries are fully exposed to Medicare's cost-sharing requirements and lack the protection of an annual limit on out-of-pocket spending, unlike beneficiaries enrolled in Medicare Advantage."

Considerations re: Medicare Advantage

Beneficiaries have the option to receive their Medicare coverage through a participating private Medicare Advantage (MA) plan. There are both advantages and disadvantages to individuals choosing to enroll in MA plans See, generally, Center for Medicare Advocacy website at: https://medicareadvocacy.org/medicare-info/medicare-advantage/; also see, specifically, Center for Medicare Advocacy publication "Choosing Between Traditional Medicare and Medicare Advantage" available at: https://medicareadvocacy.org/choosing-between-traditional-medicare-and-a-medicare-advantage-plan/.

Individuals with disabilities who are contemplating enrolling in an MA plan should consider several issues, including the findings of researchers and oversight agencies, including:

- Quality outcomes in MA plans are mixed; e.g., while research suggests higher rates of preventive care and screenings among MA recipients than those in traditional Medicare, "[s]omewhat counterintuitively, there seems to be no difference between Medicare and [MA] plans with respect to care coordination" and "[s]everal studies have flagged concerns about the quality of care received by high-need, high-cost enrollees, on the basis of disenrollment rates and other measures." *See* "Medicare Advantage Checkup", *New England Journal of Medicine* (Nov. 2018) – citation: N Engl J Med 2018; 379:2163-2172 DOI: 10.1056/NEJMhpr1804089, available at: https://www.nejm.org/doi/pdf/10.1056/NEJMhpr1804089; *also see, e.g.*, a *Health Affairs* article from May 2020 finding that "people with greater levels of disability were more likely to switch to traditional Medicare, compared to those with lower levels […] the highest-need older adults with disability may experience lower-quality care in Medicare Advantage and thus leave before accessing the program's expanded benefits." "Switching Between Medicare Advantage And Traditional Medicare Before And After The Onset Of Functional Disability" doi:10.1377/hlthaff.2019.01070HEALTH AFFAIRS 39,NO. 5 (2020): 809–81; *also see* citations in INQUIRY Journal, "Commentary: Don't Further Privatize Medicare" by David Lipschutz, Center for Medicare Advocacy (Aug. 2019) https://journals.sagepub.com/doi/10.1177/0046958019867612
- Prior authorization use in MA plans is high - the number of enrollees in plans that require prior authorization for one or more services increased from 2019 to 2020, from

79% in 2019 to 99% in 2020 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/

- MA denials of coverage and payment – a 2018 Department of Health and Human Services, Office of Inspector General (OIG) report found "'widespread and persistent problems related to denials of care and payment in Medicare Advantage' plans"; the report's findings include: "when beneficiaries and providers appealed preauthorization and payment denials, MA plans "overturned 75 percent of their own denials" however, "beneficiaries and providers appealed only 1 percent of denials to the first level of appeal." OIG, "Medicare Advantage Appeal Outcomes and Audit Findings Raise Concerns About Service and Payment Denials" (Sept. 2018) available at: https://oig.hhs.gov/oei/reports/oei-09-16-00410.pdf
- Although MA plans must impose an out-of-pocket cap on beneficiary expenses for items/services covered under Parts A and B, a recent report analyzing beneficiary costs in Medicare found that "[o]verall, a larger percentage of beneficiaries enrolled in Medicare Advantage plans reported problems getting care due to cost or paying medical bills than beneficiaries in traditional Medicare, even after controlling for income and health status." Kaiser Family Foundation, "Problems Getting Care Due to Cost or Paying Medical Bills Among Medicare Beneficiaries" (April 2020): https://www.kff.org/medicare/issue-brief/problems-getting-care-due-to-cost-or-paying-medical-bills-among-medicare-beneficiaries/

Limitations on Rights to Purchase Medigap Plans

Medicare Supplement Insurance, also known as "Medigap" insurance, provides supplemental health insurance coverage for Medicare beneficiaries. Individuals in traditional Medicare may want to obtain Medicare Supplement ("Medigap") insurance because Medicare often covers less than the total cost of the beneficiary's health care. These policies are sold by private insurance companies and fully or partially cover Part A and Part B cost-sharing requirements, including deductibles, copayments, and coinsurance. See, generally, Center for Medicare Advocacy website at: https://medicareadvocacy.org/medicare-info/medigap/.

Unfortunately, younger Medicare beneficiaries with disabilities face significant obstacles to purchasing Medigap policies. These hurdles come in the form of restricted access to Medigap coverage and prohibitive premium costs.

Federal law requires insurance companies that sell Medigap policies to abide by certain consumer protection requirements. 42 U.S.C. 1395ss(s). However, these only apply to Medicare beneficiaries who are 65 and older. Individual states, however, have the latitude to offer varying degrees of consumer protections that affect the availability of Medigap plans to younger beneficiaries with disabilities. Unfortunately, many states do not elect to extend these protections to the very people who need them the most.

For more information, *see* Center for Medicare Advocacy Weekly Alert "Barriers to Medigap Coverage for Beneficiaries Under Age 65" (October 2016), available at: https://medicareadvocacy.org/barriers-to-medigap-coverage-for-beneficiaries-under-age-65/; *also see* Kaiser Family Foundation, "The Gap in Medigap" (Sept. 2016), available at: https://www.kff.org/medicare/perspective/the-gap-in-medigap/.

## IV. SELECTED ACCESS to CARE ISSUES

Diminishing Home Health Benefit

Background

For several years, the Center for Medicare Advocacy has been hearing from people unable to access Medicare-covered home health care, or the appropriate amount of care, despite meeting Medicare coverage criteria.

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 are struggling with too little care, or no care at all.

Home health access problems have ebbed and flowed over the years, depending on the reigning payment mechanisms, systemic pressures, and misinformation about Medicare home health coverage. Regrettably, if recent policies and proposed rules are fully implemented, it appears these access problems will only get worse.

To respond to this crisis, the Center is building a coalition to support a *Home Health Access Initiative*. This *Initiative* is working to oppose inappropriate restrictions on Medicare to open doors to Medicare-covered, necessary home care, but we need your help.

If you or someone you know has experienced home health care access issues, submit the story at: https://www.medicareadvocacy.org/submit-your-home-health-access-story/.

In addition, it is important for beneficiaries and advocates to know what Medicare home health coverage should be under the law, especially for those with long term, chronic, and debilitating conditions. See our:

- Infographic: https://www.medicareadvocacy.org/wp-content/uploads/2018/04/Home-Healthcare-Infographic-r4-18-0404.pdf
- Fact Sheet: https://www.medicareadvocacy.org/fact-sheet-medicare-home-health-coverage-in-light-of-jimmo-v-sebelius/ and
- Toolkit: Medicare Home Health Coverage & *Jimmo v. Sebelius*: https://www.medicareadvocacy.org/toolkit-medicare-home-health-coverage-jimmo-v-sebelius/

See, generally, the Center's website at: http://www.medicareadvocacy.org/medicare-info/home-health-care/.

Between April 2017 and October 2018, the Center completed the "CMA Issue Brief Series: Medicare Home Health Crisis" – a ten-part series examining the growing crisis in access to Medicare home health coverage and necessary care – and outlining the Center for Medicare Advocacy's work to address these issues. The issue briefs are available online here: http://www.medicareadvocacy.org/cma-issue-brief-series-medicare-home-health-care-crisis/.

Also see the Center for Medicare Advocacy's Issue Brief "Medicare & Family Caregivers" (June 2020), available at: https://medicareadvocacy.org/issue-brief-regarding-medicare-and-family-caregivers/ (note that some the following text is excerpted from this issue brief).

## Home Health Care Coverage Rules

### a. 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:

- 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.

42 U.S.C. §§1395f(a)(2)(C), 1395x(m); 42 C.F.R. §§409.42, et seq.

b. 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:

- 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.

42 U.S.C. §1395x(m)(1)-(4).

Home Health Aide Coverage Continues to Shrink

The ability to get Medicare-covered home health aide care has greatly declined in recent years. This is true even when individuals meet the law's homebound and skilled care requirements – and thus qualify for coverage. Sadly, and incorrectly, Medicare beneficiaries are often told the only aide care they can get is a bath, and only a few times a week. Sometimes they are told Medicare simply does not cover home health aides. The Center has even heard of an individual being told he could not receive home health aide care because he was "over income" – although Medicare has no such income limit (see case study in separate article below).

In fact, Medicare law authorizes up to 28 to 35 hours a week of home health aide (personal hands-on care) and nursing services combined. 42 USC §1395x(m)(1)-(4). 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. 42 CFR §409.45(b)(1)(i)-(v). (See also, Medicare Benefit Policy Manual, Chapter 7, §§50.1 and 50.2.)

This level of home health aide personal care used to be available. The Center helped many clients remain at home because these services were in place, but now such care is almost never obtainable. Statistics demonstrate this point. In 2019 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%. MedPAC, Report to Congress, (March 2019), Ch. 9, pp. 234-235.

The real, personal, impact of this reduced access to home health aides has recently been made clear in a 2019 *Kaiser Health News* article, (Judith Graham, "Seniors Aging In Place Turn To Devices And Helpers, But Unmet Needs Are Common", 2/14/2019). The article includes striking 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.)
- 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 be receiving needed help through Medicare, it is likely that far more qualify than are accessing 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."

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.

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. Unfortunately, the financial motivations are often harmful to vulnerable beneficiaries, particularly those with chronic conditions and longer-term health care needs.

- 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/.

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. 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."

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.

### A. *Jimmo v. Sebelius* and the Improvement Standard

*Jimmo v. Sebelius*, No. 5:11-CV17 (D. Vt., 1/24/2013), was a nationwide class-action lawsuit brought against the Centers for Medicare & Medicaid Services (CMS) on behalf of individuals with chronic conditions who had been denied Medicare coverage on the basis that they were not improving or did not demonstrate a potential for improvement. In 2013, a U.S. District Court approved the settlement agreement, which required CMS to confirm that **Medicare coverage is determined by a beneficiary's need for skilled care, not on a beneficiary's potential for improvement**. Plaintiffs were represented by the Center for Medicare Advocacy and Vermont Legal Aid.

The *Jimmo* Settlement applies to all Medicare beneficiaries throughout the country, regardless of whether an individual is in traditional Medicare or has a Medicare Advantage plan.

Because of the *Jimmo* Settlement, Medicare policy now clearly states that coverage:

> [D]oes not turn on the presence or absence of a beneficiary's potential for improvement, but rather on the beneficiary's need for skilled care. Skilled care may be necessary to improve a

patient's condition, to maintain a patient's current condition, or to prevent or slow further deterioration of the patient's condition. CMS Transmittal 179, Pub 100-02, 1/14/2014.

The *Jimmo* settlement applies in the following health care settings:

1. Home health;
2. Skilled nursing facilities;
3. Outpatient therapy; and
4. Inpatient rehabilitation hospitals/facilities

Note: While improvement is a coverage criterion for inpatient rehabilitation hospitals/facilities, the *Jimmo* Settlement means that coverage in this setting does not depend on the individual's ability to achieve complete independence in self-care or a prior level of functioning.

For more information, *see, generally*, CMA website re: *Jimmo* and Improvement Standard: https://medicareadvocacy.org/medicare-info/improvement-standard/. Also see the Center's Self-Help Materials, which include *Jimmo*-related information, at https://medicareadvocacy.org/take-action/self-help-packets-for-medicare-appeals/.