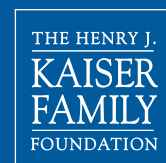


NAVIGATING MEDICARE AND MEDICAID, 2005

A Resource Guide
for People with
Disabilities,
Their Families,
and Their Advocates



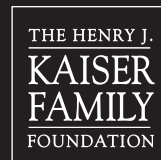
February 2005

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February 2005

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Congress created Medicare and Medicaid in 1965 to provide health coverage to two fairly distinct groups of Americans: workers who reach age 65 (that is, senior citizens) and certain groups of low-income people. While much has remained constant in Medicare and Medicaid in the past 40 years, both programs have evolved significantly. Collectively, they have come to play a major role in providing health care coverage and long-term services and supports for people of all ages with disabilities.

This guide explains the critical role Medicare and Medicaid have come to play in the lives and the futures of roughly 20 million children, adults, and seniors with disabilities—and gives people with disabilities new information to help them navigate these complex and confusing programs.

Who Should Read and Use This Guide

The individuals who will benefit most from reading this guide are individuals with disabilities, and their families, friends, and advocates. Medicare and Medicaid are extremely complicated and confusing programs—and the details of how the programs work directly affect the lives of the people with disabilities who the programs serve. Nonetheless, this guide is intended to be understandable to people who are completely unfamiliar with Medicare and/or Medicaid.

Medicare and Medicaid provide health coverage and long-term services and supports to roughly one-third of the estimated 53 million people with cognitive, developmental, physical, and/or mental disabilities in the United States. Generally, these are people with severe disabilities and extensive need for health and long-term services.

People with disabilities and their friends and advocates need to learn enough about these complex programs to navigate them and to work for policy improvements so these programs continue to evolve and meet the needs of people with disabilities more effectively.

This guide does not provide you with a complete understanding of every aspect and complexity of the Medicare and Medicaid programs. Both writing and reading such a long—and boring—encyclopedia would prove an arduous, if not impossible, task. Rather, our hope is to offer you a sound introduction to the basics of Medicare and Medicaid and the income assistance programs that provide a pathway to receiving Medicare and Medicaid.

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Medicare is a federal health insurance program that serves 41 million people, 35 million of whom are age 65 or older, and 6 million are under 65 and have permanent disabilities.

At least a third of Medicare beneficiaries of all ages—or some 13 million people¹—have disabilities or a long-term illness that limits their daily independence. About 7 million of these beneficiaries are retired Americans and their dependents, and the other 6 million Medicare beneficiaries are persons under age 65 who have worked, but have become disabled.

Medicare helps to pay for a broad array of routine, acute, and preventive care; rehabilitation, mental health, and home health services; and durable medical equipment essential to the health and independence of such beneficiaries. However, Medicare’s coverage of long-term care is limited to post-acute care through its skilled nursing facility benefit and home health care benefit.

Accessing these services and supports is crucial to enabling millions to avoid far more costly hospitalization and long-term institutionalization. Moreover, without Medicare, millions of Americans—especially people with disabilities and chronic conditions—likely would be unable to obtain or afford any health insurance at all.

¹ Includes those with a “serious” chronic condition (i.e., 3 or more ADLs, dementia). Source: *One-Third at Risk: The Special Circumstances of Medicare Beneficiaries with Health Problems*, Marilyn Moon and Matthew Storeygard, The Urban Institute, 2001.

Contacting Medicare

Medicare is administered by a federal agency, the Centers for Medicare and Medicaid Services (CMS), which is part of the U.S. Department of Health and Human Services. To get answers to questions you may have about Medicare or to order official government publications, you can contact Medicare by telephone or online.

**Telephone (toll free): 1-800-Medicare
(1-800-633-4227)**

1-877-486-2048 TTY

Website: www.medicare.gov

Who is eligible for Medicare?

Medicare is a program for eligible workers and retirees. Persons are eligible for Medicare when they turn 65 if they have worked and paid into the Social Security system or if their spouse has paid into the system. Certain workers who become severely disabled before age 65 and no longer can work are also eligible for Medicare. These individuals, however, must wait for 29 months from the time the Social Security Administration determines they have a severe and permanent disability until they can begin to receive benefits.

The Medicare law exempts two groups of nonelderly individuals from the waiting period: persons with amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease) and persons with end-stage renal disease (ESRD or kidney failure). These individuals qualify for Medicare coverage soon after they have been determined to have a permanent disability.

Additionally, certain dependent adult children of Medicare beneficiaries are eligible for Medicare if they developed a permanent and severe disability before age 22. The two-year waiting period applies and starts when an individual turns 18 (or when he or she is determined to be disabled if it is after age 18). Spouses and dependents can also continue to receive Medicare after the death of the primary Medicare beneficiary.

What must an individual do when he or she turns 65 to receive Medicare?

Persons who are receiving Social Security benefits when they turn 65 are entitled to Medicare Part A and Part B and will automatically be enrolled in both A and B on the first day of the month they turn 65. A Medicare card will arrive in the mail about three months before their birthday. Individuals can choose to decline Part B coverage, but they should take it if they want full Medicare benefits.

Persons who are still working at age 65, and believe they may not need Part B because they have health coverage under an employer plan, should check with their local Social Security office before declining Part B to be sure they will not have to pay a penalty

for late enrollment if they lose employer coverage. Individuals may elect to delay Part B enrollment at age 65 if they are still working for a company with 20 or more employees and they have health coverage under an employer plan. They will then avoid duplicating Part B coverage and paying the Part B monthly premium. Such persons will not incur any premium penalties for waiting to enroll in Part B, as long as they do so before they lose coverage under their employer plan or within eight months after losing their employer coverage.

Persons who are citizens or permanent residents, but who are not entitled to Medicare (for example, because they did not work enough years to meet the work history requirements), may still enroll voluntarily in Medicare. However, they must pay a monthly premium for Part A benefits (\$206/month for persons with 30–39 quarters of coverage, and \$375/month for persons with less than 30 quarters of coverage, in 2005). Persons who are entitled to, but who are not receiving, Social Security benefits, must apply for Medicare, because they will not be enrolled automatically. They may apply at any Social Security office during the initial enrollment period, which begins three months before they turn 65, includes the month of their birthday, and ends three months after they turn 65.

When can minor children of Social Security recipients receive Social Security benefits?

Dependent minor children of Social Security beneficiaries (including legally adopted children and dependent step children or grandchildren) are eligible for dependent benefits when a parent starts receiving Social Security benefits. If the parent dies, children can continue receiving benefits (called survivor benefits). Both dependent and survivor benefits continue until age 18 (or age 19 if the dependent remains in school). Dependent and survivor benefits are provided to all dependent children, without regard to whether or not the children have disabilities.

What Social Security rules apply to adults disabled since childhood?

Social Security benefits for dependent children normally stop when a child reaches age 18 (or 19 if the child is a full-time student). These benefits can continue to be paid into adulthood, however, if the child is disabled. To qualify for these benefits, an individual must be eligible as the child of someone who is getting Social Security retirement or disability benefits (or Medicare), or the child of someone who has died, and that child must have a disability that began before age 22.

Can minors receive Medicare?

Yes, but only in very limited circumstances. The only minors that are eligible to enroll in Medicare at any time in their youth are those with end stage renal disease (ESRD) who are not subject to the waiting period.

Can adults disabled since childhood receive Medicare?

Yes. Because such children are nonelderly, however, the Medicare waiting period applies. Medicare eligibility rules for persons under age 65 with disabilities require individuals to have received Social Security disability benefits for five months before becoming Medicare eligible. Once they have received Social Security disability for five months, they must wait another 24 months for Medicare coverage to begin. Therefore, the earliest age that such a young adult can start to be covered by Medicare is 20.

What is the process for applying for Medicare for people under age 65 with disabilities?

The first step in establishing eligibility for Medicare for persons under age 65 is to apply for and receive Social Security Disability Insurance (SSDI). To do this, an individual should go to their nearest Social Security field office.

SSDI provides monthly cash payments for individuals whose disabilities prevent them from working. Payments are based on the worker's contributions to Social Security through payroll tax deductions.

People under age 65 must be certified to be disabled for five months before receiving SSDI payments. An individual becomes eligible for Medicare only after he or she has received SSDI for 24 months. Therefore, an individual must wait 29 months from first being determined to be disabled until he or she qualifies for Medicare.

Finding Your Local Social Security Office

To find your local Social Security office or to get answers to your questions, you have three easy options for contacting the Social Security Administration (SSA):

Online: Go to <http://s3abaca.ssa.gov/pro/foi/foi-home.html>. Enter your zip code and you will be able to obtain office location, phone number, office hours, and other useful information.

By toll-free telephone call: Call 1-800-772-1213. Social Security operates this number from 7 a.m. to 7 p.m., Monday through Friday. If you have a touch-tone phone, recorded information and services are available 24 hours a day, including weekends and holidays.

By toll-free TTY telephone call: Call 1-800-325-0778. This number, for people who are deaf or hard of hearing, is available between 7 a.m. and 7 p.m., Monday through Friday.

Callers should have their Social Security number available when calling Social Security.

What are the requirements for being classified as having a disability, for purposes of applying for Medicare?

Social Security pays only for total disability. No benefits are payable for partial or short-term disability.

Not all physical and mental impairments meet the standard of disability. For example, drug addiction and alcoholism are not qualifying conditions. Further, people with several disabling conditions only meet the criteria once the conditions are in an advanced stage. For example, persons with HIV generally do not qualify until they have advanced HIV/AIDS. The same is true for persons with multiple sclerosis and other progressively disabling conditions.

Social Security's Disability Standard

For an adult to be considered disabled, the SSA must determine that the individual cannot engage in any “substantial gainful activity” because of a physical or mental impairment that is expected to result in death or to continue for at least 12 months.

Since children do not work, there is a modified disability standard for children.

How does someone under age 65 apply for SSDI and Medicare?

Individuals can apply for SSDI in one of three ways:

- Complete an application online at www.ssa.gov/applyforbenefits/.
- Call SSA on its toll-free telephone number, 1-800-772-1213. Persons who are deaf or hard of hearing, can call TTY 1-800-325-0778.
- Call or visit your local Social Security office. See the box above for information on how to do this.

To make the application process go as smoothly and as quickly as possible, people applying for SSDI and Medicare should gather as much of the information and medical documentation as they can before they begin the application process.

Necessary Information to Apply for SSDI and Medicare

- Your Social Security number and proof of your age
- Names, addresses, and phone numbers of doctors, hospitals, clinics, and institutions that have treated you and the dates of treatment
- Names of all medications you are taking
- Medical records from your doctors, therapists, hospitals, clinics, and caseworkers
- Laboratory and test results
- A summary of where you worked and the kind of work you did
- Your most recent W-2 form, or your tax return if you're self-employed

Information about Family Members:

- Social Security numbers and proof of age for each person applying for benefits
- Dates of prior marriages if your spouse is applying

IMPORTANT: You will need to submit original documents or copies certified by the issuing office. You can mail or bring them to Social Security. Social Security will make photocopies and return your original documents to you. If you don't have all the documents you need, don't delay filing for benefits. Social Security will help you get the information you need.

How much can an individual earn and continue to be eligible for Social Security benefits?

Social Security evaluates the work activity of persons claiming or receiving disability benefits under Social Security Disability Insurance. In 2005, a Social Security Disability beneficiary can earn \$830 per month and remain eligible for benefits (\$1,380/month for persons who are blind). SSA uses the term “substantial gainful activity” (SGA) to determine if work is substantial enough to make a person ineligible for benefits. Under the new rule, monthly SGA earnings limits are automatically adjusted annually based on increases in the national average wage index. This amount applies to people with disabilities other than blindness.

Can a person with a disability on Medicare and/or Medicaid be employed?

Yes, under certain conditions. Until fairly recently, federal law has made it extremely difficult for individuals with disabilities to be competitively employed and still retain vital Medicare- or Medicaid-funded benefits that often make work possible. To correct this flaw, Congress has added several "work incentives" to the Social Security Act that enables beneficiaries to:

- Receive education, training and rehabilitation to start a new line of work;
- Keep some or all SSDI or SSI cash benefits while working;
- Obtain or retain vital Medicaid coverage while working; and,
- Retain existing Medicare coverage while working.

For more information on how these incentives can enable beneficiaries to work, they can:

- Read the companion document to this publication, *Keeping Medicare and Medicaid When You Work, 2005: A Resource Guide for People with Disabilities, Their Families, and Their Advocates*, available from the Kaiser Family Foundation at www.kff.org.
- For information on SSDI and SSI work incentives as well as health coverage options refer to the Social Security Administration's 2004 Red Book, available online at <http://www.ssa.gov/work/ResourcesToolkit/redbook.html>.
- Or, call the Social Security Administration at 1-800-772-1213, or for the hearing impaired, 1-800-325-0778 (TTY/TTD).

What benefits and services does Medicare provide?

Medicare consists of several program components, or parts, and each provides different benefits and services.

Medicare Consists of Multiple Parts		
	Mandatory or Voluntary	Type of Benefit
Part A	Mandatory	Hospital insurance, including skilled nursing, some home health, and hospice services
Part B	Voluntary	Physician and outpatient services, some home health care, durable medical equipment, and ambulance services
Part C	Voluntary	Alternative to receiving traditional Medicare. Beneficiaries enroll in a Medicare Advantage health plan
Part D	Voluntary	Prescription drug benefit (beginning 01/01/2006)
Parts A and B are referred to as “traditional Medicare.”		

All Medicare beneficiaries participate in the Part A program. Medicare Part A pays for hospital expenses, including hospitalizations in specialty psychiatric hospitals. Medicare Part A also pays for up to 100 days in a skilled nursing facility and for skilled home health services; for persons with a life expectancy of six months or less, it pays for hospice services. The Part B program is voluntary. When enrolling in Medicare, individuals decide whether they wish to pay a premium (\$78.20/month in 2005) and receive Part B benefits. Most Medicare

Summary of Benefits for Traditional Medicare, 2005

Part A	
Benefit	Beneficiary Pays
Inpatient hospital Days 1–60 Days 61–90 Days 91–150 Days 150+	A total of \$912 \$228/day \$456/day All costs
Skilled nursing facility Days 1–20 Days 21–100 Days 101+	No coinsurance \$114/day All costs
Home health	No coinsurance, but pays 20% of Medicare-approved amount for durable medical equipment
Hospice	Up to \$5 for outpatient prescription drugs and 5% of Medicare-approved amount for inpatient respite care
Part B	
Benefit	Beneficiary Pays
Deductible	\$110/year
Physician and other medical services MD accepts assignment MD <i>does not</i> accept assignment	*20% of Medicare-approved amount 20% of Medicare-approved amount + (up to) 15% over Medicare amount
Outpatient hospital care	Coinsurance that varies by service
Ambulatory surgical services	20% of Medicare-approved amount
X-rays; durable medical equipment	20% of Medicare-approved amount
Physical, speech, and occupational therapy	20% of Medicare-approved amount for services in hospital outpatient facilities. In other settings, there is a \$1,590 coverage limit for occupational therapy and for physical and speech-language therapy services combined
Clinical diagnostic laboratory services	No coinsurance
Home health care	No coinsurance, but pays 20% of Medicare-approved amount for durable medical equipment
Outpatient mental health services	50% of Medicare-approved amount
Preventive services	20% of Medicare-approved amount and no coinsurance for certain services, including flu and pneumococcal vaccinations
Bone mass measurement, diabetes monitoring, glaucoma screening	20% of Medicare-approved amount

Source: *Medicare and You, 2005*, Centers for Medicare and Medicaid Services.

*assignment—provider agrees to accept the Medicare-approved amount as payment in full for the good or service.

beneficiaries receive the Part B benefit. The Part B program provides medical insurance that pays for doctors' visits/services, skilled home health services, durable medical equipment, outpatient hospital services, ambulance services, and lab tests. The Part B program also covers certain preventive health care services.

Understanding Medicare Managed Care

Individuals can choose to enroll in the Part C program by enrolling in a Medicare Advantage health plan (also called a managed care organization or MCO) as an alternative to receiving Part A and Part B benefits through traditional Medicare. Medicare beneficiaries are not required to enroll in Medicare Advantage health plans.

What is managed care? Managed care is a way of getting Medicare services through a health plan that coordinates many aspects of your care. Instead of finding your own doctors and going to see any doctor who accepts Medicare, persons with Medicare Advantage agree to see only providers in the MCO's network and to follow the rules of the health plan.

Why would Medicare beneficiaries choose to enroll in a Medicare Advantage plan? Medicare Advantage health plans attract Medicare beneficiaries by promising better service and, in some cases, reduced cost-sharing or additional benefits that traditional Medicare does not cover.

What are important issues for people with disabilities to consider? People with disabilities often have complex needs that can be difficult to address by health care programs that provide services to mostly healthy people. Some features of managed care, however, create special challenges for people with disabilities. One of the key features of managed care plans is that they frequently limit beneficiaries to a closed network of providers. Since there are often only a few qualified providers with the specialized skills for and experience in treating people with specific types of disabilities in a community, closed networks create a risk that people with disabilities will not have access to all of the types of providers they need, or they may not be able to continue seeing their current doctor.

For additional information, see the Kaiser Family Foundation's website resources on Medicare Advantage at www.kff.org.

When people speak of “traditional Medicare,” they generally refer to the Part A and B programs.

The Part C program is a voluntary program providing options to enroll in a Medicare managed care program. The Part C program was also called Medicare+Choice. In 2003, Congress renamed the Part C program the Medicare Advantage program.

Does Medicare cover prescription drugs?

Congress has recently enacted a new voluntary Medicare Part D program to provide a Medicare outpatient prescription drug benefit. This new benefit will not be available until January 1, 2006. Until then, there is an interim Medicare-approved drug discount card and transitional assistance program. The new law also includes other changes for beneficiaries, including new preventive benefits, increases in the Part B deductible (beginning in 2005); and, beginning in 2007, increases in the Part B premium for beneficiaries with incomes over \$80,000 (single) and \$160,000 (couple).

Beginning June 2004 (and ending by January 2006), Medicare beneficiaries have access to Medicare-approved drug discount cards, estimated to produce savings of 10 percent to 15 percent overall, although no minimum discount is required. Enrollees can sign up for only one Medicare-approved card per year. For beneficiaries with incomes below 135 percent of poverty (\$12,569 for a single person or \$16,862 for a couple in 2004)² who do not have private or Medicaid drug coverage, the government provides \$600 per year for drug expenses in 2004 and 2005 and pays the annual discount card enrollment fee.

Medicare will pay for outpatient prescription drugs through private plans beginning in January 2006. Beneficiaries can remain in traditional Medicare and enroll separately in a private prescription drug plan, or they can enroll in a Medicare Advantage plan that also covers prescription drugs.

Under the standard benefit, beneficiaries in 2006:

- Pay the first \$250 in drug costs (deductible).
- Pay 25 percent of total drug costs between \$250 and \$2,250.
- Pay all drug costs between \$2,250 and \$5,100 in total drug costs.

² The federal government updates poverty guidelines annually. At the time of publication, poverty guidelines for 2005 were not yet available. To find the latest poverty guidelines, go to <http://aspe.hhs.gov/poverty/poverty.shtml>.

- Pay either \$2 for generics and \$5 for brand drugs or 5 percent of total drug spending (whichever is greatest) for all drug spending greater than \$5,100 in drug spending.

What are some gaps in Medicare’s benefits package?

While Medicare is a major payor for health care services, it has significant gaps in coverage, including:

- Outpatient prescription drugs (until Medicare drug coverage starts in 2006)
- Personal assistance services
- Institutional services
- Dental care and dentures
- Hearing aids
- Routine eye care and eyeglasses
- Routine foot care
- Many screening tests
- Bathroom grab bars and similar equipment

Even when Medicare covers a particular service or piece of equipment, it sometimes places restrictions on such coverage that can limit the independence of people with disabilities. These are discussed below.

How do people with disabilities obtain these services if Medicare does not cover them?

Assistance may be available under Medicaid for people with disabilities if their income is low enough. Persons who receive both Medicare and Medicaid are known as “dual eligibles” (see page 39 for more information). For many people with disabilities, Medicaid provides a critical supplement to Medicare, filling in Medicare’s gaps in coverage.

Supplemental insurance is sometimes available, and some Medicare beneficiaries also have access to retiree health benefits provided by their previous employer that supplements Medicare’s benefits package. Medigap, or Medicare supplemental insurance, may also be available to provide supplemental benefits to some people with disabilities who are receiving Medicare. Under federal law, Medicare beneficiaries age 65 and over have a right to obtain Medigap coverage, but the law denies this protection to Medicare beneficiaries under age 65 with disabilities.

Only a small number of states require insurers that provide Medigap coverage in their state to offer it to nonelderly people with disabilities.

To learn if Medigap coverage is available to people with disabilities under age 65 in your state, you can contact your State Health Insurance Assistance Program. For contact information, go to www.healthassistancepartnership.org.

What should I know about the skilled nursing facility (SNF) benefit?

After an inpatient hospital stay of three days or more, you may be eligible for services in a skilled nursing facility (SNF). If you receive services in a SNF, Medicare covers a semiprivate room, meals, skilled nursing and rehabilitative services, and other services and supplies. The benefit is limited to 100 days. There is no deductible for SNF services; however, you must pay \$114 a day for days 21–100. The Medicare SNF benefit will pay for short-term skilled care that you require to recover from being hospitalized for an illness or injury. The SNF benefit may reduce the time you are hospitalized after an illness, injury, or surgery by providing skilled care in a less expensive post acute care setting.

Medicare also pays for medical social work and discharge planning services that can help an individual make the necessary arrangements for leaving a SNF once he or she is able to do so. This can include helping the person find, apply for, and schedule services and supports needed to move out of the facility and live in the community. A medical social worker and discharge planner also can help a person leaving a SNF to arrange for ramps, grab bars, and other needed modifications to make his or her home or apartment accessible and livable and to find a new, accessible home or apartment to move into after leaving the SNF.

What should I know about skilled home health services?

To obtain home health services, a doctor must certify that you need skilled nursing care or therapy services on a part-time or intermittent basis. Medicare defines skilled care as medically reasonable and necessary care performed by a skilled nurse or therapist. Examples of skilled nursing care can include wound care (for example, treating pressure sores, catheterization, or changing a tracheotomy tube).

The physician must send a referral or letter of certification to a Medicare-certified home health agency. After receiving this referral, the home health agency sends a nurse to the individual's home to evaluate him or her and establish a plan of care.

Under such a plan of care, a beneficiary can receive both skilled care and a limited number of home health aide visits each week. Home health aides can assist a

person with such tasks as bathing, dressing, using the bathroom, and eating. Medicare pays for this assistance but only when the individual has an underlying skilled care need. In other words, the Medicare home health benefit does not pay for home health aide services for those whose sole need is for personal assistance with the types of daily activities just mentioned.

There are also other limits on the amount of service you can receive under the Medicare home health benefit. As a rule, services cannot exceed eight hours a day or 35 hours a week. Depending on an individual's need, Medicare home health services can be provided for only a few days or over a period of several years if these basic qualifying requirements continue to be met.

Medicare pays for home health services for any beneficiary who needs skilled nursing care, therapy, and home health aide services due to an acute, advanced (that is, terminal), or chronic (ongoing) condition, as long as the person is "homebound."

What is the homebound rule?

Enacted in the early 1970s, the homebound rule defines who is eligible to receive Medicare home health services. To be considered "homebound:"

1. The individual must have "a normal inability to leave home."
2. Leaving home must require "a considerable and taxing effort by the individual," typically by relying on a wheelchair, cane, or the assistance of another person.
3. The person may leave home for *any reason*, but most absences outside the home must be of an "infrequent or of relatively short duration."

The law also specifically permits an individual to be absent from his or her home, at any time, to receive health care or to attend adult day care or religious services.

The third criterion is often applied in a restrictive manner by home health agencies and/or Medicare fiscal intermediaries. Such entities sometimes try to require that those receiving home health services will be discharged and found not to need skilled care if they leave home for any reason other than a limited number of visits for a few specific purposes, such as going to a doctor. But, this interpretation is at odds with the actual language of the law, which allows individuals to leave home for any reason of their choice so long as it is for an "infrequent or of relatively short duration."

Another reason why the homebound rule is often interpreted in a restrictive manner is that deciding when an absence from home constitutes one that is of an

“infrequent or of relatively short duration” can only be done in a very subjective and arbitrary way.

What must someone do to get Medicare to cover home health services?

If you are in the hospital: when you are told that you will be discharged from the hospital, ask to speak to a discharge planner or social worker to arrange for an evaluation by a home health agency (HHA). Your doctor may be able to initiate this process for you.

If you are at home: ask your doctor to contact a home health agency to request an evaluation. If the HHA believes that you are eligible, it can work with your doctor to develop a “plan of care.”

What is Medicare’s policy for covering durable medical equipment (DME)?

Hospital and SNFs provide medical equipment to individuals who are admitted to their facilities. To receive coverage for DME outside of a hospital or SNF, however, you must participate in the Part B program. The DME benefit category covers a broad range of items needed by people with disabilities, such as wheelchairs, augmentative communication devices, and glucose monitors. Medicare’s DME benefit also covers orthotics and prosthetics (O&P). These devices are considered medically necessary when they replace or support a body part. Certain medical supplies are also covered as DME, including oxygen, catheters, ostomy supplies, and test strips for people with diabetes.

Medicare pays for DME when:

- You have Medicare Part B.
- Your doctor prescribes a covered item of DME.
- You need the item or device to function in your home.

What DME does Medicare *not* cover?

While Medicare covers many items under its Part B DME benefit, other items are considered items of “personal convenience.” Examples of DME or supplies that are not covered by Medicare include:

- Raised toilet seat
- Shower/commode wheelchair
- Grab bars and other safety equipment for the bathroom
- Hearing aids
- Examination gloves
- Catheters

Why is DME limited to uses within the home?

Nearly 20 years ago, when Congress created Medicare Part B, it allowed the purchase of wheelchairs and other durable medical equipment (DME) only if they are used “in the person’s home.” Since the Part A program already covered DME in hospitals and SNFs, Congress did not want to pay twice for the same benefit. Federal regulations have interpreted this to mean that Medicare Part A pays for DME in hospitals and SNFs, and Part B pays for DME needed in the home, but no part of Medicare pays for DME that helps individuals to live in the community. For example, if a person can use a standard manual wheelchair inside his or her house, but actually needs a lighter weight or motorized wheelchair to be more independent and productive in the home and community, Medicare will still only pay for the standard wheelchair.

What is meant by assignment and how does this affect access to DME?

When a DME vendor is said to accept “assignment,” it means that the provider agrees to accept the Medicare-approved amount as payment in full for the good or service.

Medicare does not require beneficiaries to receive services from providers who accept assignment, but this can be an important way for beneficiaries to limit their costs.

A Medicare-certified supplier who does not take assignment can still sell medical equipment to people with Medicare. They can also charge more than the Medicare-approved amount, but they cannot charge in excess of 15 percent more

than the Medicare-approved amount. Medicare-certified suppliers also have the option of taking assignment on a case-by-case basis. It is always worthwhile to ask the supplier if he or she will help you by taking assignment. If the supplier does not take assignment for an item you need, you must pay the full cost up front. The supplier then submits a claim to Medicare, and Medicare refunds 80 percent of its approved amount directly to you.

Beware: In this case, you will end up paying 20 percent of the Medicare-approved amount plus any extra amount the supplier charges.

Does Medicare pay for routine maintenance of DME?

No. Medicare does not usually cover routine maintenance of DME, unless the DME is rented.

Does Medicare pay for replacement batteries and tires for power wheelchairs?

Medicare pays for service and maintenance for rented DME. Medicare does not pay for cleaning, testing, or regular DME equipment checkups.

For a particular item of DME, there may be a replacement schedule. For more information, contact a Durable Medical Equipment Regional Carrier (DMERC), which pays DME claims, in your state (<http://www.medicare.gov/Contacts/Home.asp>).

Does Medicare cover inpatient psychiatric services for people with mental illness?

Medicare pays for some inpatient mental health services, but there is a lifetime limit of 190 days of coverage. Traditional hospitals typically offer limited inpatient psychiatric services. If you seek mental health services from a traditional hospital, however, Medicare will not apply the cost of these services toward the lifetime limit.

Medicare also may pay for partial hospitalization services if the doctor certifies that you need it to avoid more costly inpatient treatment in a hospital.

What outpatient mental health services does Medicare pay for?

Medicare Part B pays for many mental health services. When services are

delivered specifically for the people managing their mental health, however, the individual must pay half of the cost. Unlike the 80 percent-20 percent cost-sharing structure for other Medicare Part B services, mental health services require you to typically pay half of the total cost of service.

However, Medicare Part B pays 80 percent of the Medicare-approved amount for some medical services that may be related to your mental health, including:

- Initial diagnostic services;
- Appointments with your doctor to monitor and adjust prescription medication;
- Medical management services for people living with Alzheimer's and related disabilities; and
- Services provided when participating in a partial hospitalization program.

What should Medicare beneficiaries do if they are told that Medicare will not pay for a hospital bill or for a Medicare Part A service?

Private companies, known as Medicare claims processing contractors, administer Medicare payments for the federal government. Beneficiaries can file an appeal with a Medicare claims processing contractor within 60 days of receiving notice that payment for a claim is being denied. For individuals to protect their legal rights, they must read and save all correspondence and information they are given related to the services they receive and the payment for these services. If individuals receive a notice that their payment is denied, the notice will include information about how to file an appeal. Individuals must also make sure they follow the appeal rules, including filing an appeal within the time allowed.

Do beneficiaries have rights if they are in the hospital and they are told that they are being discharged before they believe it is medically appropriate?

Yes. Medicare beneficiaries who have been hospitalized have legal protections if they are notified that the hospital or their MCO attempts to discharge them and they do not believe this is medically appropriate. This is called an immediate peer review organization (PRO) review. Medicare relies on PROs to conduct an independent assessment of whether a hospital discharge is appropriate. The right to an immediate PRO review is the same for Medicare beneficiaries in traditional Medicare and for enrollees in a Medicare Advantage MCO.

To request an immediate PRO review, beneficiaries must submit a request in writing or by telephone by noon of the first working day after they have received written notice that the MCO or hospital has determined that their care is no longer medically necessary. The PRO is authorized to review medical records and to receive other pertinent documents from both the MCO and the hospital, and it is required to solicit the views of the enrollee. It is then required to notify the enrollee, the hospital, and the MCO of its decision by close of business on the first

working day after it receives all necessary information from the MCO and the hospital.

For Medicare Advantage participants, if a beneficiary files a request for an immediate PRO review on time, and the MCO authorized the initial hospital coverage, then the MCO remains liable for all covered hospital expenses until noon of the calendar day following the PRO decision. If the enrollee wins at this level, the MCO remains liable for hospital expenses until the facility is legally able to discharge the enrollee on the basis that the hospital stay is no longer medically necessary.

What should Medicare beneficiaries do if they are told that Medicare will not pay for a doctor's bill or for any other Medicare Part B service?

Beneficiaries and Part B physicians and suppliers can file an appeal within six months of receiving notice that payment for a claim is being denied.

Part B disputes for claims totaling at least \$100 can be appealed further within six months to claims processing contractors' in-house hearing officers. Disputes over at least \$100 for home health claims and at least \$500 for all other claims can be appealed within 60 days to an administrative law judge (ALJ). As with Part A appeals, these ALJ decisions can be appealed within 60 days to the Health and Human Services Departmental Appeals Board, which can turn down appeals or review cases on its own. Within 60 days, these decisions involving at least \$1,000 can be appealed further in federal district court.

What should Medicare beneficiaries do if they are enrolled in a Medicare Advantage plan (or MCO), and they are told that the plan will not authorize or pay for a service?

Enrollees should file an appeal in such cases, if, for example, their doctor won't order a treatment that they think they need and that is covered by Medicare; if they have a problem getting a referral; if their MCO does not approve tests or procedures recommended by their primary care provider; or if their MCO will not approve a second opinion for surgery.

Medicare beneficiaries can appeal a decision by a Medicare Advantage MCO:

- to deny payment for emergency services;
- to deny payment to a provider that is not part of the MCO's network;

- to refuse to provide a covered service that a Medicare beneficiary believes is medically necessary; or
- to discontinue a service if the beneficiary believes that the service is still needed.

Enrollees may file a grievance if, for example, they believe the MCO's facilities are inaccessible, inadequate, or in poor condition, or if they did not like the way their doctor treated them. Every Medicare Advantage MCO is required to establish and operate a grievance process that provides for timely hearing and resolution of grievances. Grievances tend to involve issues that are less serious than appeals—which involve actual denials of care—and enrollees do not have a right to an external hearing of their grievances.

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Medicaid is often referred to as America's safety net for its poor. For millions of children, adults, and older Americans with disabilities, it's that and far more. For someone with a disability, being able to obtain Medicaid services and community living supports can mean:

- Receiving the personal assistance you need to get out of bed, to eat, to get dressed, and go about your day.
- Getting the epilepsy medication you need to control your seizures.
- Being able to see a mental health counselor to help your depression.
- Keeping your Medicaid even when you are competitively employed.
- Waking up in your own home instead of in a nursing home.

Medicaid is a nationwide program funded jointly by the federal government and the states. Medicaid pays for health care, institutional long-term care, and community living services for about 50 million low-income children and their families, people with disabilities, and older persons. No other public or private insurance plan covers such a comprehensive range of health care, institutional long-term care, and community living services. Medicaid is best known for the essential health care coverage it provides to poor children, but it also can play a unique and compelling role in improving the health and independence of an estimated 8.4 million low-income people with disabilities throughout the nation.

Because every state plays a significant role in financing Medicaid services, each one has broad discretion in designing and administering its Medicaid program. Within broad national guidelines set by the federal government each state:

1. Establishes its own eligibility standards.
2. Determines the type, amount, duration, and scope of services it will provide.
3. Sets the rate of payment for services.
4. Administers its own program.

Thus, the Medicaid program varies considerably between and within states. This guide provides information about federal Medicaid requirements and describes some of the ways that states can go beyond federal standards to meet the diverse needs of people with disabilities of all ages.

Who is eligible for Medicaid?

Medicaid provides health care coverage to 52.4 million people, making it the largest health care program in the country. Medicaid covers roughly 8.4 million people with severe disabilities. In general, Medicaid provides coverage for three basic groups of Americans: children and their parents, the elderly, and people with disabilities. Individuals must have low incomes, have few assets (such as money in the bank), and meet immigration and residency requirements.

Which groups of people are states required to cover under Medicaid?

State Medicaid programs must provide Medicaid to some people, called mandatory populations. These include pregnant women and children under age 6 with family incomes less than 133 percent of the poverty level (\$1,737 per month in 2004 for a family of three) and older children (age 6 to 18) with family incomes less than 100 percent of poverty (\$1,306 per month in 2004 for a family of three). States must also cover some low-income parents, as well as people with disabilities and the elderly who are eligible for the Supplemental Security Income (SSI) program or similar state set requirements. For people with disabilities to qualify for SSI, their income must be below \$579 per month in 2005 for a single individual (roughly 74% of the poverty level). In addition, states are required to assist certain low-income Medicare beneficiaries by paying their Medicare Part B premiums (\$78.20/month in 2005) and, in some cases, cost-sharing.

Which groups of people can states choose to cover (or not cover) under Medicaid?

States also have the option to cover other people, called optional populations. These include certain other groups of low-income children and their parents, people with disabilities, and the elderly with low to moderate incomes above mandatory coverage limits. For example, many states have expanded eligibility to people with disabilities up to the poverty level. An important optional coverage

group for many people with disabilities is the medically needy. Additionally, over the past decade, Congress has passed two major laws to give states the option to extend Medicaid eligibility to working people with disabilities. To learn more about eligibility policies for people with disabilities in your state, see the website of the National Association of State Medicaid Directors at www.nasmd.org/eligibility/.

How do I find out if I am eligible for Medicaid?

Since Medicaid rules can vary dramatically from one state to another, the best way to find out the specific eligibility requirements is to contact the Medicaid office in your state. Telephone, fax, and internet contact information can be found at www.cms.hhs.gov/medicaid/allStateContacts.asp. Or, for the phone numbers for the Medicaid program in your state, see the table on the next page.

Where can people with disabilities turn if they need assistance in applying for Medicaid?

Many community and national resources are available to help people with disabilities navigate the health system, including Medicaid. Individuals needing assistance are encouraged to check out the following resources:

- **Protection and Advocacy Programs.** Contact the National Association of Protection and Advocacy Systems (NAPAS) at (202) 408-9514 or www.napas.org for contact information for the protection and advocacy program in your state. The protection and advocacy system is a federally funded network that seeks to ensure that federal, state, and local laws are fully implemented to protect people with disabilities. While the capacities of state programs vary, many protection and advocacy programs actively assist people with disabilities in accessing Medicaid.
- **Health Assistance Partnership.** This program of Families USA (a national consumer advocacy organization) supports a network of consumer assistance programs (ombudsman programs) throughout the country. To find out if there is a program in your community, contact the partnership at (202) 737-6340 or infohap@healthassistancepartnership.org.
- **Disability Advocacy Organizations.** Many local, state, and national advocacy organizations assist people with disabilities to access Medicaid and resolve problems they encounter. Such organizations also may be a good way to get referrals to programs that assist people with disabilities in your community.

How to Contact Medicaid in Your State			
	Telephone	TTY	Toll-Free*
Alabama	334-242-5000		800-362-1504
Alaska	907-465-3030		
Arkansas	501-682-8292		800-482-5431
Arizona	602-417-4000	602-417-4191	800-962-6690
California	916-445-4171	916-445-0553	
Colorado	303-866-2993	303-866-3883	800-221-3943
Connecticut	860-424-4908		800-842-1508
Delaware	302-255-9040		
District of Columbia	202-442-5999		
Florida	888-419-3456		
Georgia	770-570-3300		866-322-4260
Hawaii	808-524-3370	808-692-7182	800-316-8005
Idaho	208-334-5500	208-332-7205	800-685-3757
Illinois		800-526-5812	800-226-0768
Indiana	317-233-4455		800-889-9949
Iowa	515-327-5121		800-338-8366
Kansas	785-274-4200	800-766-9012	800-766-9012
Kentucky	502-564-4321		800-635-2570
Louisiana	225-342-9500		
Maine	207-621-0087	207-287-1828	800-977-6740
Maryland	410-767-5800		800-492-5231
Massachusetts	617-628-4141		800-841-2900
Michigan	517-373-3500	517-373-3573	
Minnesota	651-297-3933	651-296-5705	
Mississippi	601-359-6050		800-880-5920
Missouri	573-751-4815		800-392-2161
Montana	406-444-4540		800-362-8312
Nebraska	402-471-3121	402-471-9570	800-430-3244
Nevada	775-684-7200		
New Hampshire	603-271-4238		
New Jersey	609-588-2600		800-792-9745
New Mexico	505-827-3100	505-827-3184	888-997-2583
New York	518-747-8887		800-541-2831
North Carolina	919-857-4011	877-733-4851	800-662-7030
North Dakota	701-328-2321	701-328-8950	800-755-2604
Ohio	614-728-3288		800-324-8680
Oklahoma	405-522-7171	405-522-7179	800-522-0310
Oregon	503-945-5772	503-945-5895	800-527-5772
Pennsylvania	717-787-1870	717-705-7103	800-692-7462
Rhode Island	401-462-5300	401-462-3363	
South Carolina	803-898-2500		
South Dakota	605-773-3495		800-452-7691
Tennessee	615-741-019	615-313-9240	800-669-1851
Texas	512-424-6500		888-834-7406
Utah	801-538-6155		800-662-9651
Vermont	802-241-2800	802-241-1282	800-250-8427
Virginia	804-786-7933		
Washington	800-562-6188		800-562-3022
West Virginia	304-558-1700		
Wisconsin	608-221-5720	608-267-7371	800-362-3002
Wyoming	307-777-7531	307-777-5578	

*For many states, toll-free numbers work in-state only.

What does it mean to be “medically needy”?

Thirty-five states plus the District of Columbia operate medically needy programs. The medically needy option allows states to provide Medicaid to certain groups of individuals who are ineligible because of excess income, but who have high medical expenses. States often use the medically needy program to expand coverage primarily to persons who spend down by incurring medical expenses so that their income minus medical expenses falls below a state-established medically needy income limit (MNIL). The opportunity to spend down is particularly important to elderly individuals living in nursing homes and children and adults with disabilities who live in the community and incur high prescription drug, medical equipment, or other health care expenses, either following a catastrophic incident or due to a chronic condition.

What does it mean that Medicaid is an entitlement?

For individuals, Medicaid’s entitlement means that all people who meet Medicaid eligibility requirements have an enforceable right to enroll in Medicaid and receive Medicaid services on a timely basis. This means that a state cannot deny Medicaid coverage to individuals if more people enroll than a state expects, nor can states have waiting lists. The exception to this applies to those receiving Medicaid services under any type of Medicaid waiver. This is discussed further below.

Further, the individual entitlement means that people enrolled in Medicaid have a right to receive all Medicaid covered services when they are medically necessary, as determined by the state. To meet this standard, a physician or qualified health professional must determine that a service is needed and the individual may also need to meet certain clinical or functional criteria. When individuals are denied Medicaid eligibility or services to which they are entitled, they can go to federal court to force states to comply with Medicaid’s rules. While rarely used, individual enforcement of Medicaid, called a private right of action, has been important in protecting people with disabilities and others in Medicaid.

Medicaid is also an entitlement to the states. This means that if states follow Medicaid rules, they have a legal right to have the federal government pay its share of Medicaid expenses. The federal share of a state’s Medicaid spending is called the federal medical assistance percentage (FMAP). The FMAP formula is based on average per capita income. States with per capita incomes above the national average receive lower matching percentages. By law, the minimum FMAP is set at 50 percent, and the maximum is set at 83 percent. To learn what your state receives in federal Medicaid spending, go to the Medicaid Spending section in the Medicaid topic at www.statehealthfacts.org.

What benefits and services does Medicaid provide?

Medicaid requires states to cover certain mandatory services, which include coverage for physician visits and hospitalizations. The early and periodic screening, diagnostic, and treatment (EPSDT) benefit for children is mandatory and ensures that children on Medicaid are screened regularly, and if a disability or health condition is diagnosed, the state must cover its treatment, even if the state does not provide the same services to adults in Medicaid. Other mandatory services include laboratory and X-ray services, nursing home coverage, and home health services (including durable medical equipment) for persons entitled to nursing home coverage.

States can also cover additional services, called optional services. These are services that are frequently needed by people with disabilities and include prescription drugs, physical therapy, personal attendants, and rehabilitation services.

Mandatory Medicaid Services

All states must cover:

- Hospital care (inpatient and outpatient)
- Physician services
- Laboratory and X-ray services
- Family planning services
- Health center and rural health clinic services
- Nurse midwife and nurse practitioner services
- Early and periodic screening, diagnostic, and treatment (EPSDT) services and immunizations for children and youth under age 21
- Nursing home care
- Home health services (including DME) for those eligible for nursing home care
- Transportation services for doctor, hospital, and other health care visits*

Most Medicaid beneficiaries are entitled to coverage for any of these services whenever they are medically necessary, as determined by the state.

*Although not included in the Medicare law as a mandatory service, transportation services are required by federal regulations.

Optional Medicaid Services

States can choose to cover the following services, and the federal government will match state spending:

Basic medical and health care services

- Prescribed drugs
- Clinic services
- Emergency hospital services
- Diagnostic services
- Screening services
- Preventive services
- Nurse anesthetists' services
- Tuberculosis-related services
- Chiropractors' services
- Private duty nursing
- Medical social workers' services

Services that support people with disabilities to live in their communities

- Personal care services
- Rehabilitative and/or clinic services
- Case management services
- Small group homes that operate as intermediate care facilities for persons with mental retardation and developmental disabilities (ICFs/MR) for 15 or fewer residents

Aids, Therapies, and Related Professional Services

- Podiatrists' services
- Prosthetic devices
- Optometrists' services
- Eyeglasses
- Dental services
- Dentures
- Psychologists' services
- Physical therapy
- Occupational therapy
- Respiratory care services
- Speech, hearing, and language therapy

Services involving short- or long-term institutional stays

- Inpatient psychiatric hospital services for children and young people under age 21
- Nursing facility services for children and young people under age 21
- At large intermediate care facilities for persons with mental retardation and developmental disabilities (ICFs/MR) with more than 15 residents
- Inpatient hospital services for persons age 65 or older with mental illness in institutions for mental diseases (IMDs)
- Nursing facility services for persons age 65 or older with mental illness in institutions for mental diseases (IMDs)

End-of-Life Care

- Hospice care services

Special treatment for children: Through the Early, and Periodic, Screening, Diagnosis, and Treatment (EPSDT) requirement, states must provide children access to all Medicaid covered services (including optional services) when they are medically necessary, whether or not they cover such services for adult beneficiaries.

All states provide coverage for many optional services. But the specific services covered and the limitations they place on the level of a benefit provided vary substantially.

To find out which optional services are available in your state (as of January 2003), the Kaiser Commission on Medicaid and the Uninsured and the National Conference of State Legislatures have developed an easy-to-use web-based tool for determining which services each state covers. Go to www.kff.org/medicaidbenefits.

What does the requirement mean that Medicaid services must be adequate in amount, duration, and scope?

Services must be provided in an amount, duration, and scope that are reasonably “sufficient” to achieve their intended purpose. States do have discretion to vary the amount, duration, or scope of the services they cover, but in all cases the service must be “sufficient in amount, duration, and scope to reasonably achieve its purpose.” For instance, a state may not limit coverage for inpatient hospital care to one day a year. Similarly, it seems unlikely that a state could provide attendant services for just five hours a week and still credibly say that this meets the benefit’s essential purpose of enabling people with disabilities to live in their own communities. Hence, this requirement provides some protection to those on Medicaid from receiving inadequate services. But states are often left to interpret on their own whether they are satisfying this critical requirement.

When people talk about Medicaid “consumer protections,” what do they mean?

Medicaid rules are intended to ensure that all people applying for Medicaid and receiving it are treated fairly. This includes requirements that services generally must be provided statewide, so that states cannot offer services to individuals in one part of the state and deny them to individuals in another. Generally, services must also be comparable. This means that, except in limited circumstances, whatever services a state covers, it must provide them equally to all Medicaid beneficiaries when they are medically necessary. This protection ensures that services are provided based on medical need and one group of Medicaid beneficiaries is not treated more favorably than others.

State Medicaid programs cannot reduce the amount, duration, or scope of mandatory services to a beneficiary “solely because of the diagnosis, type of illness, or condition.” This protects beneficiaries from arbitrary limitations on

services and ensures that covered services are provided at an adequate level to be effective. The Medicaid program also guarantees Medicaid applicants and beneficiaries due process rights to ensure that individuals are treated fairly and that they have the right to appeal any decisions denying them eligibility or services if they disagree with these decisions.

What are Medicaid waivers?

Waivers are programs that allow the Secretary of Health and Human Services to permit individual states to receive federal matching funds without complying with certain Medicaid rules (such as the consumer protections described above). Unlike regular Medicaid services, waiver services can be provided to specific targeted populations or to persons in limited parts of a state.

What are home- and community-based services (HCBS) waivers? How do these programs differ from regular Medicaid programs?

The 1915(c) waiver, also called the home and community-based services (HCBS) waiver, is the most frequently used waiver for providing services in the community. These waivers are available to Medicaid-eligible individuals who, without the waiver services, would be institutionalized in a hospital or nursing facility. This type of waiver allows the Secretary to waive certain financial eligibility requirements and the Medicaid requirement that services must be “comparable” among beneficiaries and must be provided statewide. The Secretary also has the authority (which is regularly invoked) to impose enrollment caps to ensure the budget neutrality of HCBS waivers. This is done to prevent waivers from increasing federal Medicaid costs.

What are 1115 demonstration waivers? How do these programs differ from regular Medicaid programs?

The 1115 demonstration waiver gives the Secretary the broadest authority to waive compliance with Medicaid rules. While Congress has proscribed the waiving of certain parts of the Medicaid law, the 1115 demonstration authority gives the Secretary broad discretion to approve waiver programs that are “likely to assist in promoting the objectives” of the Medicaid law. States have used 1115 demonstrations to make changes to Medicaid that affect the entire Medicaid program. This type of waiver can also be used to waive Medicaid rules that cannot be waived under the 1915(c) waiver program. Recently, some states have sought to make wholesale changes to Medicaid through this type of waiver, in some cases

asking essentially to eliminate the entitlement to Medicaid services. People with disabilities and their advocates have frequently opposed these types of waivers, which have resulted in capped funding for Medicaid services.

Why can't all people in Medicaid receive services in the community?

One of the shortcomings of Medicaid is that it has an institutional bias, meaning Medicaid funds are more likely to pay for institutional services rather than those that are provided in someone's home and community. This is because nursing home coverage is mandatory, but coverage of the same types of services that are available in the community is optional.

While waivers have enabled states to experiment with different ways of providing community-based services, using them invariably results in significant inequities both across and within states in what people with disabilities receive. This, in turn, has led to long waiting lists to receive services in the community.

How do the Americans with Disabilities Act (ADA) and Medicaid relate to each other?

Like all other public programs, the ADA requires that states administer Medicaid in a manner that does not discriminate against individuals with disabilities who are eligible for the health care and long-term services the program offers. To do this, states must take steps to ensure that persons on Medicaid with disabilities receive such services in the most integrated setting appropriate to their needs. This is known as the ADA integration mandate.

In its *Olmstead v. L.C.* decision, the U.S. Supreme Court ruled that the needless and unjustified institutionalization of people with disabilities is discriminatory, saying that institutionalizing a person who could live in his or her community with services and supports is a form of discrimination and segregation banned by the ADA. The Court further held that the practice violates the ADA requirement that services be provided to such individuals in the most integrated setting appropriate to their needs. To meet their obligations under the ADA, states must both remedy such discrimination when it has occurred and prevent it from taking place in the future.

The Court's decision did not prohibit the institutional placement of Medicaid beneficiaries, and the ADA does not require states to make "fundamental alterations" in its services or programs. Further, the Court provided a defense against lawsuits claiming a violation of the standards articulated in the *Olmstead*

decision by saying that a comprehensive, effectively working plan for placing qualified individuals in less restrictive settings, with a waiting list that moves at a reasonable pace not controlled by a state's efforts to keep its nursing homes full, would meet the requirements of the *Olmstead* decision. But the key requirement of the decision, and the ADA, itself, is to take reasonable actions to rectify the discrimination today.

What is managed care?

Managed care is a way of getting services through a health plan that coordinates many aspects of your care. Instead of finding their own doctors and seeing *any* doctor who accepts Medicaid, individuals must agree to follow the managed care organization's (MCO) rules, which often include seeing only certain providers who participate in the MCO's network. Individuals generally also have a primary care provider (PCP) who is their main doctor and who must give his or her approval before an individual can see specialists.

What types of managed care programs operate in Medicaid?

While managed care exists in many forms, there are two dominant models for such care: capitated managed care and primary care case management (PCCM) programs.

Capitated managed care programs transfer the risk for paying for health care services from the payor (that is, the state Medicaid agency) to organizations that contract with the payor to deliver health care services, called managed care organizations (MCOs). Commonly, MCOs, in turn, often transfer some of the risk for paying for health care services from the MCO to physicians or other health care providers. Capitation involves paying an established fee on a per person per month basis for all persons enrolled in an MCO, whether or not an individual receives any services. In exchange, the MCO accepts responsibility for delivering all medically necessary services covered under the contract between the state Medicaid agency and the MCO. PCCM programs use many of the management techniques of MCOs, and Medicaid programs pay the PCCM agency a fee for providing management services. Unlike capitated programs, however, PCCMs are not at risk for the cost for health services, and Medicaid agencies continue to pay for health care services on a fee-for-service basis.

Can a Medicaid program require a beneficiary to enroll in a managed care program?

Yes. Congress enacted the Balanced Budget Act of 1997 (BBA), which paved the way for greater use of managed care in Medicaid. Previously, states that wanted to require Medicaid beneficiaries to enroll in managed care programs had to request federal permission, through a waiver. Now, states can require most Medicaid beneficiaries, except children with special health care needs and dual eligibles (*i.e. persons enrolled in both Medicare and Medicaid*), to enroll in an MCO without getting federal approval for this requirement.

What rights do applicants and beneficiaries have to appeal Medicaid decisions?

Medicaid beneficiaries must receive “due process” whenever benefits are denied, reduced, or terminated. The Supreme Court has defined essential components of due process for Medicaid to include: prior written notice of adverse action, a fair hearing before an impartial decision-maker, continued benefits pending a final decision, and a timely decision measured from the date the complaint is first made.

Medicaid also gives applicants and beneficiaries additional rights:

1. The right to request a fair hearing by a state agency for any individual who has been found ineligible for benefits, has been denied benefits, or whose request for services has not been acted upon with reasonable promptness.
2. The right to file an internal grievance within an MCO.
3. Medicaid beneficiaries may enforce their rights in federal court through a private right of action. This refers to an individual filing suit against a state Medicaid program in federal court claiming the state is denying him or her a right guaranteed by federal law.

What is a Medicaid fair hearing?

There are fairly detailed requirements mandating how states can satisfy the fair hearing requirement. Medicaid applicants have the right to a hearing if they believe their application has been denied or if the states have not given them a decision within a reasonable amount of time. Beneficiaries who have enrolled in Medicaid have a right to a hearing if they believe the state Medicaid agency has made an incorrect decision, such as denying coverage for a service they believe they need.

In most states, the state fair hearing decision can be appealed in state court.

What additional appeals rights apply to persons enrolled in a Medicaid MCO?

Medicaid beneficiaries can dispute MCO decisions or other features of the MCO in two ways: they can appeal an action or they can file a grievance. An action includes MCO activities, such as denying a service, refusing to pay for a service, reducing or suspending the amount of a service it will authorize, or failure to act in a timely manner on a request for a service. MCO enrollees can also file a grievance if they are dissatisfied with activities of the MCO that are not actions. For example, if a health care worker treats an MCO enrollee rudely, or if the enrollee is unhappy with the quality of services received, the enrollee can file a grievance.

MCOs are required to give enrollees reasonable assistance in completing forms and taking other procedural steps. This includes providing interpreter services, when necessary, and ensuring access to toll-free TTY/TTD telephone lines.

MCOs must consider and resolve grievances and appeals as quickly as the enrollee's health requires, within state-established time frames. The maximum time an MCO has to resolve a grievance is 90 days, and the maximum time to resolve an appeal is 45 days. There is also a process for expedited appeals if a regular appeal would "seriously jeopardize the enrollee's life or health or ability to attain, maintain, or regain maximum function." The general standard for expedited appeals is three working days.

What is the relationship between the managed care grievance and appeal process and the right to a fair hearing?

Medicaid beneficiaries enrolled in MCOs have a right to a state fair hearing, but the state is permitted to decide whether it will require beneficiaries to go through the managed care appeals process before having access to a fair hearing. This is called an exhaustion requirement.

In states without an exhaustion requirement, the state must allow individuals to request a fair hearing within a reasonable time frame (decided by the state). At a minimum, the state must allow an individual to request a fair hearing not less than 20 days from the date of notice of the MCO's action. In no case can a beneficiary request a fair hearing more than 90 days after the date of notice of the MCO's action.

States with an exhaustion requirement can set a reasonable time frame for allowing individuals to request a fair hearing that is no less than 20 days and no more than 90 days from the date of notice of an MCO's resolution of an appeal.

Where can people with disabilities turn if they need assistance navigating the appeals process?

Many community and national resources are available to help people with disabilities navigate the health system, including Medicaid. Individuals needing assistance are encouraged to check out the following resources:

- **Protection and Advocacy Programs.** Contact the National Association of Protection and Advocacy Systems (NAPAS) at (202) 408-9514 or www.napas.org for contact information for the protection and advocacy program in your state. The protection and advocacy system is a federally funded network that seeks to ensure that federal, state, and local laws are fully implemented to protect people with disabilities. While the capacities of state programs vary, many protection and advocacy programs actively assist people with disabilities in accessing Medicaid.
- **Health Assistance Partnership.** This program of Families USA (a national consumer advocacy organization) supports a network of consumer assistance programs (ombudsman programs) throughout the country. To find out if there is a program in your community, contact the partnership at (202) 737-6340 or infohap@healthassistancepartnership.org.
- **Disability Advocacy Organizations.** Many local, state, and national advocacy organizations assist people with disabilities to access Medicaid and resolve problems they encounter. Such organizations also may be a good way to get referrals to programs that assist people with disabilities in your community.

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Interaction between Medicare and Medicaid

More than 7 million people receive both Medicare and Medicaid; these individuals are called “dual eligibles” or “dual enrollees.” While these people rely on Medicare for basic health services, Medicaid plays an essential role in paying Medicare’s premiums and cost-sharing and in covering critical services not covered by Medicare, including prescription drugs and long-term services and supports.

How does an individual become a dual eligible?

As discussed in previous sections, individuals are determined to be disabled by the Social Security Administration. People with permanent disabilities who have an adequate work history qualify for Medicare after the waiting period. Most people age 65 and over qualify for Medicare. As discussed earlier, certain adults who acquire disabilities in childhood sometimes qualify for Medicare if their parents are covered by Medicare.

Full Benefit Dual Eligibles

The vast majority of dual eligibles (6.4 million) receive full Medicaid benefits. People with disabilities can also qualify for varying levels of assistance from Medicaid if their income is low enough. Persons who receive SSI—or persons in states that have expanded Medicaid eligibility to persons with disabilities up to the poverty level—qualify for full Medicaid coverage that supplements Medicare’s coverage, pays the Part B premium, pays any Medicare cost-sharing, and provides services not covered by Medicare such as long-term care.

Medicare Saving Program (MSP) Dual Eligibles

Medicare beneficiaries with disabilities with slightly higher incomes and limited assets can also qualify for partial benefits from Medicaid:³

³ The federal government updates poverty guidelines annually. At the time of publication, poverty guidelines for 2005 were not yet available. To find the latest poverty guidelines, go to <http://aspe.hhs.gov/poverty/poverty.shtml>.

- Persons with incomes up to 100 percent (\$776 per month in 2004) of the poverty level can qualify as Qualified Medicaid Beneficiaries (QMBs, pronounced “quimbies”). These individuals do not receive Medicaid supplemental benefits, but Medicaid does pay their Medicare Part B premium and cost-sharing.
- Persons with incomes between 100 percent and 120 percent (\$776–\$931 per month in 2004) of the poverty level qualify as Specified Low-Income Beneficiaries (SLMBs, pronounced “slimbies”). Medicaid pays the Part B premium for SLMBs.
- Block grant funding is available to states for Qualifying Individual (QI) coverage for individuals with incomes between 120 percent and 135 percent (\$931–\$1,046 per month in 2004) of the poverty level. Medicaid pays the Part B premium for QIs. Because this program is a block grant, this benefit is subject to having sufficient funding and is not guaranteed to all individuals.

For information and help on determining whether you maybe eligible for this type there assistance, you should contact the State Health Insurance Assistance Program nearest you. For a list of where these programs are located, go to <http://www.medicare.gov/contacts/static/allStateContacts.asp>. Or, call 1-800-Medicare (1-800-633-4227), or 1-877-486-2048 TTY.

How are dual eligibles different from other Medicare beneficiaries?

Most dual eligible individuals have very low incomes: 77 percent have an annual income below \$10,000, compared to 18 percent of all other Medicare beneficiaries. High-cost and sick or frail Medicare beneficiaries are concentrated among the dual eligibles. Nearly one in four dual eligibles is in a nursing home, compared to 3 percent of other Medicare beneficiaries, and one-third of dual eligibles have significant limitations in their activities of daily living (ADLs), compared to 12 percent of other Medicare beneficiaries.

What does it mean to be a primary and/or secondary payor?

When an individual has two sources of payment for the same service, one source must be billed first. This is the primary payor. In the case of dual eligibles, Medicare is the primary payor and Medicaid is the secondary payor, supplementing payments made by Medicare.

In 2003, Congress enacted a Medicare reform law that included a prescription drug benefit. How does this law affect dual eligibles?

The new Medicare law establishes a Medicare prescription drug benefit (Part D) that becomes effective on January 1, 2006. On this date, a major transition occurs: Medicaid will no longer provide drug coverage; rather individuals will have to enroll in a Medicare Part D prescription drug plan. Starting in January 2006, Medicaid programs are prohibited from receiving federal Medicaid funds to provide prescription drug benefits to persons who are eligible for Medicare. However, Medicaid coverage will remain important to dual eligibles, because they will still be able to receive other services through Medicaid, such as long-term care.

The legislation establishes a transitional drug discount program that is available until the drug benefit is implemented. Persons who have access to Medicaid drug coverage are ineligible to participate in the discount program. The drug discount card program expires the day before the new drug benefit goes into effect.

Selecting and enrolling in a Part D plan prior to January 1, 2006 is very important for dual eligibles. Otherwise, these individuals will be randomly assigned to a Part D plan.

The drug coverage provided under Medicare Part D will not necessarily be the same as what dual eligibles currently receive under Medicaid and could differ dramatically depending on the state in which they reside and on how Part D is implemented.



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