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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 your 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.

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.

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.

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.

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