Medicare and Medicaid Programs

Medicare. Title XVIII of the Social Security Act, designated “Health Insurance for the Aged and Disabled,” is commonly known as Medicare. As part of the Social Security Amendments of 1965, the Medicare legislation established a health insurance program for aged persons to complement the retirement, survivors, and disability insurance benefits under Title II of the Social Security Act.

Medicare covers individuals age 65 and older, people under age 65 with certain disabilities, and individuals with end-stage renal disease. Coverage of respite care is limited to Medicare Hospice Benefits and Medicare Advantage Special Needs Plans. Both of these programs are described in detail following this introduction.

Medicaid. Title XIX of the Social Security Act is a federal and state entitlement program that pays for medical assistance for certain individuals and families with low incomes and resources. This program, known as Medicaid, became law in 1965 as a cooperative venture jointly funded by the federal and state governments (including the District of Columbia and the Territories) to assist states in furnishing medical assistance to eligible needy persons. Medicaid is the largest source of funding for medical and health-related services for America’s poorest people.

Each state submits a plan that describes how it intends to administer its Medicaid program. Included in the plan is a list of services to be funded. States are required to cover inpatient hospital services, some outpatient hospital services, laboratory and x-ray services, nursing facilities, and some physician’s care services, as well as services provided by authorized midwives and pediatric nurses. The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program is mandatory for eligible children up to age 21. The legislation also contains an extensive list of other services that states may choose to include in their plans.

Medicaid will pay for home and community-based services (HCBS) through the state plan as well as through Medicaid waivers. In 2012, three main Medicaid HCBS programs provided access to long-term services and supports for more than 3.2 million people. Most of the growth has occurred through waiver programs. Almost 1.5 million individuals were served through §1915(c) waivers in 47 states and DC, 764,487 individuals received care through the home health state plan benefit in 50 states and DC, and 944,507 individuals received the personal care state plan services benefit in 32 states (see Medicaid Personal Care Benefit in this section).¹

Increasingly, states are electing to offer services through the self-direction model, which includes initiatives to allow the beneficiary to choose how to allocate their own budgets for services and/or allow them to select and dismiss their providers. In 2014, 42 states with §1915(c) waivers permitted or required self-direction in at least one waiver, 24 states permitted self-direction in personal care state plans, and 9 states allowed self-direction in home health state plan services.²

Historically, federal regulations limited the ability of states to cover the cost of respite care directly

² Ibid., 2015.
as a regular Medicaid benefit under the state plan because it was considered a nonmedical expense. One exception, begun in 1985, was the Medicaid Hospice option.

A number of research, demonstration, and waiver programs under Medicaid continue to allow states to provide respite as one of the home and community-based services offered as a lower-cost alternative to treatment in a medical facility. These include

- **Section 1115 Research and Demonstration Projects,**
- **Section 1915(b) Managed Care/Freedom of Choice Waivers,**
- **Section 1915(c) Home and Community-Based Services Waivers,** and
- **Money Follows the Person (MFP) Demonstration Grants.**

In addition, Medicaid has made available several state options that pay for personal care services for consumers and provide an opportunity for family caregivers to receive a break from their duties:

- **Medicaid Personal Care Benefit,**
- **Section 1915(j) Self-Directed Personal Assistance Services,**
- **Programs of All-Inclusive Care for the Elderly (PACE),** and
- **Section 1915(i) Medicaid State Plan Option for Home and Community-Based Services**

The Affordable Care Act made improvements to several of the options listed above and authorized a new Medicaid state plan option to provide home and community-based attendant services and supports (known as Community First Choice [CFC]).

Each of these programs, demonstrations, and waivers is described in this and the following section.
Medicare Hospice Benefits

Authorizing legislation:
Title XVIII of the Social Security Act.

Program purpose:
Hospice care is a program of support and care for individuals who are terminally ill and their families. Hospice is chosen to provide comfort rather than cure at the end of life.

Funding:
Medicare pays for covered services using daily capitated rates.

Activities supported by the funding:
Medicare covers a range of hospice services, generally at home, from a team that may include doctors, nurses, counselors, other medical professionals, social workers, aides, homemakers, and volunteers. In addition, inpatient respite care from a hospice in a Medicare-approved facility is available when the patient’s usual family caregiver needs a rest.

Respite connection:
Respite for family caregivers is a core service of the program. Individuals receive hospice care in a Medicare-approved facility to give family caregivers a break. Such respite stays can last up to 5 days at a time, and there is no limit to the number of times respite can be used. There is a co-payment for respite services, which is 5% of the Medicare-approved amount for inpatient respite care.

Issues for consumers, providers, and advocates:
The hospice benefit is available only to individuals who

- are eligible for Medicare Part A (Hospital Insurance),
- have been certified by a doctor and hospice medical director to be terminally ill with 6 months or less to live if the illness runs its normal course,
- have signed a statement choosing hospice care instead of other Medicare-covered benefits that would treat the illness, and
- receive care from a Medicare-approved hospice program.

A co-payment of 5% of the Medicare-approved amount for inpatient respite care is required.

Federal funding agency:
U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services (CMS).

Eligibility:
Individuals eligible for Medicare who meet the hospice requirements.

Points of contact:
A map of Regional Home Health Intermediaries (RHHIs) can be downloaded from page three of this CMS website:
A list of state hospice organizations can be found on the Hospice Directory website.  
http://www.hospicedirectory.org/cm/about/state_hospice

Related links:  
http://www.eldercare.gov/ELDERCARE.NET/Public/Resources/Factsheets/Hospice_Care.aspx

References:  
Medicare Advantage Special Needs Plans (SNPs)

Authorizing legislation:
Title XVIII of the Social Security Act, as amended by

- Medicare Modernization Act (MMA) of 2003;
- Medicare, Medicaid, and SCHIP [State Children's Health Insurance Program] Extension Act of 2007;
- Medicare Improvements for Patients and Providers Act (MIPPA) of 2008;
- Patient Protection and Affordable Care Act (the ACA);
- Section 607 of the American Taxpayer Relief Act of 2012 (ATRA); and

Currently authorized through:
December 31, 2015.

Program purpose:
To improve care for certain vulnerable groups of Medicare beneficiaries.

Beneficiaries:
Medicare beneficiaries who are institutionalized, those who are dually eligible (covered by both Medicare and Medicaid), and those with certain disabling or chronic conditions (limited to 15 specific conditions at the present time). These beneficiaries are typically older with multiple conditions and are therefore more challenging and costly to treat.

Funding:
SNPs are a specialized Medicare Advantage (Part C) program.

Activities supported by the funding:
Plans must cover all of the medically necessary services and preventive services covered under Medicare Parts A and B and prescription drug coverage under Part D. They may cover additional services tailored to the special groups being served. Chronic conditions currently approved for SNPs are

- chronic alcohol and other drug dependence,
- certain autoimmune disorders,
- cancer (excluding pre-cancer conditions),
- certain cardiovascular disorders,
- chronic heart failure,
- dementia,
- diabetes mellitus,

• end-stage liver disease,
• end-stage renal disease requiring dialysis,
• certain hematologic disorders,
• HIV/AIDS,
• certain chronic lung disorders,
• certain mental health disorders,
• certain neurologic disorders, and
• stroke.

Respite connection:
Plans may offer respite for family caregivers of patients who do not live in institutions.

Issues for consumers, providers, and advocates:
Not all SNPs provide the same coverage for the same individuals; consumers should find out specific information about any plan (use the Medicare Plan Finder below under Related links).

Federal funding agency:

Points of contact:
Use the Medicare Plan Finder (see below under Related links) or call 1-800-MEDICARE (1-800-633-4227) to find an SNP in your area. TTY users can call 1-877-486-2048.

Related links:
Medicare Plan Finder.
https://www.medicare.gov/find-a-plan/questions/home.aspx

HealthCare.gov.
http://www.healthcare.gov/

References:

http://www.medicare.gov/Publications/Pubs/pdf/11302.pdf


Medicaid Personal Care Benefit

Authorizing legislation:
Title XIX of the Social Security Act.

Program purpose:
To provide coverage of personal care services to some individuals eligible for Medicaid. States may choose to include this option in their state Medicaid plan for adults over age 21 but must provide these services to individuals under age 21.

Beneficiaries:
Low-income persons who are over age 65, blind, or disabled; members of families with dependent children; low-income children and pregnant women; and certain Medicare beneficiaries. In many states, medically needy individuals may apply to a state or local welfare agency for medical assistance. Eligibility is determined by the state in accordance with federal regulations.

Funding:
When a state elects an optional service, it is obliged to provide that benefit to its entire eligible population, as needed, and to pay its share of the cost of the service. As of October 1, 2012, 30 states and the District of Columbia included this optional benefit in their state plan.4

Activities supported by the funding:
“Personal care services furnished to an individual who is not an inpatient or resident of a hospital, nursing facility, intermediate care facility for the mentally retarded, or institution for mental disease that are (A) authorized for the individual by a physician in accordance with a plan of treatment or (at the option of the State) otherwise authorized for the individual in accordance with a service plan approved by the State, (B) provided by an individual who is qualified to provide such services and who is not a member of the individual’s family, and (C) furnished in a home or other location.”5

Respite connection:
Although the personal care benefit does not specifically include respite, while the consumer is receiving personal care services, other family caregivers can take a break from caregiving. States therefore have the option of providing respite to their entire eligible population indirectly through the personal care benefit.

Issues for consumers, providers, and advocates:
Federal rules require states to provide equal access for all eligible Medicaid recipients to all services in a state Medicaid plan. If a state includes personal care as part of its plan, then any individual who meets the state Medicaid eligibility guidelines must have access to personal care.

Respite care providers may legitimately label themselves “personal care providers” as long as they comply with applicable state guidelines. For information about how providers can apply for recognition as a provider of Medicaid personal care, contact the director of Medicaid for your state.

5 Section 1905(a)(24) of the Social Security Act, as amended.
For information about whether the Personal Care Option is part of a state’s Medicaid Plan, visit the state Medicaid website (see Points of contact below) or check the Kaiser Family Foundation Online Database (see Related links below).

Federal funding agency:

Eligible entity:
State Medicaid Agency.

Points of contact:
A map with links to state Medicaid program websites is available from the National Medicaid Directors Association. http://medicaiddirectors.org/about/medicaid-directors/

Related links:
Catalog of Federal Domestic Assistance: Medical Assistance Program.
https://www.cfda.gov/index?s=program&mode=form&tab=core&id=c095abf249685c0320745b57ad49ba41

Kaiser Family Foundation Medicaid Benefits Online Database.
http://medicalbenefits.kff.org/service.jsp?yr=5&so=0&cat=1&sv=28&gr=off&x=53&y=12

References:
**Section 1915(j) Self-Directed Personal Assistance Services**

**Authorizing legislation:**
Title XIX of the Social Security Act, as amended by the Deficit Reduction Act of 2005.

**Program purpose:**
To give frail elders and adults with disabilities the option to manage a flexible budget and decide for themselves what mix of goods and services will best meet their personal care needs. In some states, children with developmental disabilities are also served. This option allows states to include such services under their Medicaid state plans rather than through Section 1915(c) waivers.

**Beneficiaries:**
Medicaid-eligible frail elders, children, and adults with disabilities, depending on the state.

**Funding:**
At the state’s option, funds are allocated directly to consumers (via budgets), who are then free to decide how they wish to spend their personal care dollars. Participants receive a monthly allowance or budget based on what Medicaid would otherwise have paid to the regular service vendors. States can also choose to require Financial Management Entities to conduct all activities related to cash disbursement, payroll functions, tax functions, and so on.

**Activities supported by the funding:**
Self-directed personal assistance services (other than room and board) may be considered to be “medical assistance” for eligible individuals. This can include help with everyday needs such as bathing, dressing, grooming, cooking, and housekeeping.

**Respite connection:**
Consumers can hire personal caregivers of their choice in order to provide respite for their regular family caregivers.

**Issues for consumers, providers, and advocates:**
Cash & Counseling, now more commonly known as participant-directed services, began as a Section 1115 waiver (see Section 1115, Research and Demonstration Projects, Medicaid Waivers) and is now a state option available under the Medicaid State Plan.

§1915(j) programs include both “budget authority,” meaning the consumer or family directs a personal budget and has flexibility to purchase goods and services other than attendant care, and “employer authority,” which conveys to the consumer/family the authority of hiring, firing, and supervising individual aides or attendants of their choosing.

Consumers may use their budgets to hire anyone they choose, including a relative, to provide that care. However, some states do not permit payment to persons legally responsible for the participant’s care; this would generally exclude spouses. Some states do permit such payments.

Participant-directed programs may be operating under Medicaid home and community-based services (HCBSs) waivers, other demonstration or waiver programs (see Medicaid Waivers) or under other programs. There is considerable variation by and even within states.

**Federal funding agency:**
Points of contact:
Contact information for each state is available through an online interactive map.
https://nrcpds.bc.edu/insights-publications.php

Related links:
National Resource Center for Participant-Directed Services, Cash & Counseling.
http://www.bc.edu/schools/gssw/nrcpds/cash_and_counseling.html

http://www.payingforseniorcare.com/longtermcare/resources/cash-and-counseling-program.html

References:
http://www.mathematica-mpr.com/~/media/publications/PDFs/ccpersonalcare.pdf

Programs of All-Inclusive Care for the Elderly (PACE)

Authorizing legislation:

Program purpose:
To enable individuals needing nursing home care to remain in the community; to provide flexible service delivery to those individuals.

Beneficiaries:
Participants must be age 55 or older, live in the PACE service area, and be certified as eligible for nursing home care by the state. The PACE Innovation Act of 2015, which was enacted in November 2015, allows the Centers for Medicare & Medicaid Services (CMS) to develop pilots using the PACE Model of Care to serve individuals under age 55 and those at risk of needing a nursing home (Public Law 114-85).6

Funding:
PACE is a capitated benefit with integrated Medicare and Medicaid financing. PACE providers receive monthly Medicare and Medicaid payments for each enrollee. Medicare enrollees who are not eligible for Medicaid pay monthly premiums equal to the Medicaid capitation amount. The PACE program is a unique capitated managed care benefit for the frail elderly provided by a not-for-profit or public entity.

Activities supported by the funding:
The PACE program offers a comprehensive medical and social service delivery system using an interdisciplinary team approach in an adult day health center, supplemented by in-home and referrals services, based on participants’ needs. PACE programs must be provided by a not-for-profit or public entity and include all Medicaid and Medicare covered services plus “all other services determined necessary by the health professionals team to improve and maintain an individual’s health.”7 As of 2015, there were 114 PACE programs in 32 states8 serving more than 34,413 enrollees.9

Respite connection:
A PACE program can incorporate caregiver services, including caregiver training and support groups, into the care plan and make respite services available to caregivers.10 In addition to breaks available to family caregivers during the provision of services at an adult day health center, respite may be available as a service determined to be necessary by the consumer’s interdisciplinary team.

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9 National PACE Association, PACE Census and Capitation Rate Survey, January 2015 (information obtained over the telephone on June 2, 2015)

Issues for consumers, providers, and advocates:
PACE becomes the sole source of services for Medicare and Medicaid for eligible enrollees.

Federal funding agency:

Points of contact:
A list of PACE Provider Organizations is available at
http://www.npaonline.org/pace-you/find-pace-program-your-neighborhood

Related links:
National PACE Association.
http://www.npaonline.org/website/article.asp?id=5&title=About_NPA

Kaiser Family Foundation Medicaid Benefits Online Database: Program for All Inclusive Care for the Elderly.

References:
Centers for Medicare & Medicaid Services. PACE Fact Sheet.
Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program

Authorizing legislation:
Title XIX of the Social Security Act.

Program purpose:
To provide a comprehensive and preventive child health care program for individuals under the age of 21.

Beneficiaries:
Medicaid-eligible children under age 21.

Funding:
EPSDT is a required program for all state Medicaid plans.

Activities supported by the funding:
EPSDT must include
- comprehensive health and developmental history and physical examination,
- appropriate immunizations,
- state-identified laboratory tests for specific ages or populations,
- lead toxicity screening,
- health education and counseling for parents and children,
- vision diagnosis and treatment,
- dental examination and some treatments,
- hearing diagnosis and treatment, and
- “Other necessary health care, diagnosis services, treatment, and other measures…to correct or ameliorate defects, and physical and mental illnesses and conditions discovered by the screening services.”

Respite connection:
Even if personal care benefits are not included in a state’s Medicaid plan, children and young people up to age 21 can receive personal care benefits under the EPSDT provision. When a Medicaid-eligible child has a diagnosis indicating a “medical necessity” for any required or optional Medicaid service, the state is obligated to provide the service. As with the personal care option, while the consumer is receiving personal care services, other family members can take a break from caregiving if they are permitted to leave the home.

Issues for consumers, providers, and advocates:
When consumers reach age 21, they are no longer eligible for EPSDT. Availability of personal care services for adults may differ from those provided under EPSDT, depending on the individual’s eligibility as well as services provided in the state.
**Federal funding agency:**

**Eligible entity:**
State Medicaid Agency.

**Points of contact:**
A list of state Medicaid program websites is available from the National Medicaid Directors Association website. [http://medicaiddirectors.org/about/medicaid-directors/](http://medicaiddirectors.org/about/medicaid-directors/)

**Related links:**
Catalog of Federal Domestic Assistance: Medical Assistance Program.
[https://www.cfda.gov/index?s=program&mode=form&tab=core&id=c095abf249685c0320745b57ad49ba41](https://www.cfda.gov/index?s=program&mode=form&tab=core&id=c095abf249685c0320745b57ad49ba41)

Centers for Medicaid and Medicare. *Early and Periodic Screening, Diagnostic and Treatment Benefit*
[http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html](http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html)

Health Resources and Services Administration. *EPSDT and Title V Collaboration to Improve Child Health.*

**References:**
Medicaid Hospice Benefits

Authorizing legislation:
Title XIX of the Social Security Act.

Program purpose:
To provide palliative care for individuals with terminal illnesses.

Beneficiaries:
Medicaid-eligible individuals with terminal illnesses.

Funding:
States may choose to include this option in their state Medicaid plan to adults over age 21 but must provide this service to individuals under age 21. When a state elects an optional service, it is obliged to provide that benefit to its entire eligible population, as needed, and to pay its share of the cost of the service.

Activities supported by the funding:
In general, Medicaid hospice benefits parallel the Medicare hospice benefit (see Medicare Hospice Benefits) although there may be some variations in certain states. As of 2012, 42 states offered hospice care as a covered Medicaid benefit.

Respite connection:
For Medicaid-eligible individuals, hospice care is an optional benefit that may be available if chosen by the state. Patients who reside in a nursing facility may receive hospice care in that setting. Respite is available to family caregivers who are caring for the patient at home on an occasional basis and for no more than 5 consecutive days at a time. Respite is not available if the patient is a resident of a nursing facility.

Issues for consumers, providers, and advocates:
As with the Medicare Hospice Benefit, the consumer must be terminally ill, elect to receive palliative care (rather than treatment) for that illness, and receive care from an approved program. Section 2302 of the Affordable Care Act amended the Medicaid hospice benefit to implement a concurrent care provision for children. Individuals under age 21 are no longer required to forgo curative treatment of the terminal illness upon election of Medicaid hospice.

Federal funding agency:

Eligible entity:
State Medicaid Agency.

Points of contact:
A list of state Medicaid program websites is available from the National Medicaid Directors Association website. http://medicaiddirectors.org/about/medicaid-directors/
Related links:
Catalog of Federal Domestic Assistance: Medical Assistance Program.
https://www.cfda.gov/index?s=program&mode=form&tab=core&id=c095abf249685c0320745b57ad49ba41

Kaiser Family Foundation Medicaid Benefits Online Database
http://kff.org/medicaid/state-indicator/hospice-care/

References:
Center for Medicare and Medicaid Services, Hospice Benefits.
http://www.medicaid.gov/medicaid-chip-program-information/by-topics/benefits/hospice-benefits.html

Medicaid Waiver Programs

The Social Security Act authorizes several different waiver and demonstration opportunities for states to operate their Medicaid programs with some flexibility. Each authority has its own purpose and requirements. States have used a variety of waivers to expand Medicaid eligibility and to adopt new models of coverage and care delivery.

Four separate types of waivers are available to states:

- **Section 1115, Research and Demonstration Projects,**
- **Section 1915(b), Managed Care/Freedom of Choice Waivers,**
- **Section 1915(c), Home and Community-Based Services Waivers,** and
- **Combined Sections 1915(b) and 1915(c) Waivers.**

Medicaid Waivers are by far the largest source of federal funds for respite. All states have §1915(c) HCBS waivers except Arizona, Rhode Island and Vermont, which operate their long-term care programs under Section 1115 demonstration waivers. However, in most states, long waiting lists for services prevail. In 2014, 39 states reported a total of 582,066 people on waiting lists across 154 §1915(c) waivers. This included 349,511 individuals with intellectual/developmental disabilities and 155,000 persons waiting for aged/disabled waiver services. The national average time an individual was on a §1915(c) waiting list was 29 months, with the average ranging from 4 months for mental health waivers (available only in 5 states in 2012) to 47 months for intellectual/developmental disabilities waivers.\(^\text{11}\)

Many states are currently making changes to their Medicaid waivers, by moving toward capitated managed care for long-term services and supports (MLTSS). Medicaid MLTSS programs can be operated under multiple federal Medicaid managed care authorities at the discretion of the state and as approved by CMS, including §1915(a), §1915(b), and §1115.\(^\text{12}\) The majority of states are implementing Medicaid MLTSS through §1115 demonstrations or §1915(b)/(c) waivers.\(^\text{13}\) As of September 2015, 26 states were providing long-term services and supports through managed care.\(^\text{14}\)

For a full list of current state waiver programs, see the Medicaid Waivers and Demonstrations List on the Centers for Medicare & Medicaid Services website.

http://www.cms.gov/MedicaidStWaivProgDemoPGI/MWDL/list.asp

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Section 1115 Research and Demonstration Projects

**Authorizing legislation:**
Title XXI, Section 1115 of the Social Security Act.

**Program purpose:**
To demonstrate and evaluate policies or approaches that have not been widely implemented, including expanded eligibility guidelines, coverage of services not typically provided, or innovation in service delivery systems.

**Funding:**
State Medicaid agencies submit applications, often working with the Centers for Medicare & Medicaid Services to develop the proposal. Demonstrations typically run 5 years and may include continuations beyond that time. Demonstrations must be budget neutral, not costing the federal government more than they would without the waiver.

**Activities supported by the funding:**
Initiatives under this authority are intended to demonstrate a wide variety of new health care services delivery methods. Successful demonstrations may lead to broader implementation of innovations. For example, the Medicaid Cash & Counseling Option (described above in Section 1915(j) Self-Directed Personal Assistance Services) began as a Section 1115 waiver in 1998 in three states. Increasingly, states are using 1115 waivers to implement Medicaid managed care for long-term services and supports. As of 2012, three states (Arizona, Rhode Island, and Vermont) use §1115 waivers exclusively to administer statewide Medicaid managed care programs that include all covered HCBS for all populations. Another five states (Delaware, Hawaii, New York, Tennessee, and Texas) use §1115 waivers for Medicaid managed care programs that include HCBS for at least some geographic areas and/or populations as well as §1915(c) waivers for HCBS services in other geographic areas and/or populations.\(^{15}\)

**Respite connection:**
State waivers could expand services to include respite and/or eligibility to individuals and families in need of that service.

**Example:** Tennessee has been operating its Section 1115 waiver, TennCare, since 1994. It has received multiple extensions and is currently approved through June 30, 2013. TennCare provides coverage statewide to many populations, including children under 21, pregnant women, some low-income families with children, Supplemental Security Income recipients, and some other low-income adults. There are several packages within TennCare that provide different coverage of services such as home health services when medically necessary. In 2010, home and community-based services have been folded into TennCare’s CHOICES program for long-term care for individuals in nursing homes as well as adults age 65 or older and younger adults who have physical disabilities who receive home care. CHOICES includes coverage for personal care visits, attendant care, adult day care, and both in-home and inpatient respite care. [Source: Tennessee. (2010). TennCare. http://www.tn.gov/tenncare/](http://www.tn.gov/tenncare/)

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**Issues for consumers, providers, and advocates:**
Proposals are subject to approval by the Centers for Medicare & Medicaid Services (CMS), Office of Management and Budget (OMB), and U.S. Department of Health and Human Services (DHHS) and may be subject to additional requirements such as site visits before implementation. CMS does not have a specific timeframe to approve, deny, or request additional information on the proposal. Additionally, CMS usually develops terms and conditions that outline the operation of the demonstration project when it is approved.

**Federal funding agency:**

**Eligible entity:**
State Medicaid Agency.

**Points of contact:**
A list of state Medicaid program websites is available from the National Medicaid Directors Association website. [http://medicaiddirectors.org/about/medicaid-directors/](http://medicaiddirectors.org/about/medicaid-directors/)

**Related links:**
Center for Medicare and Medicaid Services, Section 1115 Demonstrations
[http://www.cms.gov/MedicaidStWaivProgDemoPGI/MWDL/list.asp](http://www.cms.gov/MedicaidStWaivProgDemoPGI/MWDL/list.asp)

**References:**
Centers for Medicare & Medicaid Services (CMS). Section 1115 Demonstrations.
Section 1915(b) Managed Care Waivers

Authorizing legislation:
Title XIX, Section 1915(b) of the Social Security Act.

Program purpose:
To allow states to implement managed care delivery systems or otherwise limit choice of providers under Medicaid.

Funding:
The Centers for Medicare & Medicaid Services has 90 days to act on applications submitted by state Medicaid agencies, with a second 90-day review period if necessary, after which the application is deemed approved. Programs must be “cost-effective,” which means that the state’s actual expenditures under a waiver are less than the state’s projected budget for the program. Waivers are approved for 2-year periods, which may be extended indefinitely through renewal applications.

Activities supported by the funding:
States may

- mandate enrollment in managed care programs,
- allow local governments to act as an enrollment broker,
- use cost savings to provide additional services, or
- limit the number or type of providers for services.

Respite connection:
States can use the authority to provide additional services to specify respite as one of those additional services.

Federal funding agency:

Eligible entity:
State Medicaid Agency.

Points of contact:
A list of state Medicaid program websites is available from the National Medicaid Directors Association website.  http://medicaiddirectors.org/about/medicaid-directors/

Related links:
Section 1915(c) Home and Community-Based Services Waivers

Authorizing legislation:
Title XIX, Section 1915(c) of the Social Security Act.

Program purpose:
To allow states to provide home and community-based services (HCBS) to individuals who would otherwise require institutional nursing care.

Funding:
States apply to Centers for Medicare and Medicaid Services (CMS) for an initial HCBS waiver for a 3-year period; renewals are at 5-year intervals. Applications must show that providing these services to the target population will not exceed the cost of institutional care.

Activities supported by the funding:
In addition to traditional medical services, states can also provide services not usually covered by the Medicaid program as long as these services are required to keep a person from being institutionalized. Services covered under waiver programs include case management, homemaker, home health aide, personal care, adult day health, habilitation, and respite care. Family members and friends may be providers of waiver services if they meet the specified provider qualifications. However, in general, spouses and parents of minor children cannot be paid providers of waiver services.

Respite connection:
Respite is specifically supported by this waiver authority. It is the leading source of federal funds for respite care for those who are eligible.

All states have HCBS waivers except Arizona, Rhode Island and Vermont, which operate their long-term care programs under Section 1115 demonstration waivers. There is no federal requirement limiting the number of HCBS waiver programs a state may operate at any given time, and in 2014, there were 293 HCBS waiver programs in operation throughout the country. Most states include respite within one or more of their Section 1915(c) Medicaid Waiver Programs.

Issues for consumers, providers, and advocates:
Depending on how individual waivers are written by the state, waiver programs generally are narrowly targeted to individuals of specific ages with specific disabilities, illnesses (such as AIDS), or conditions (such as head injury). The “Aging and Disabled Waiver” is the most common waiver for respite services for the aging population.

However, in 2014, CMS published a final rule that permits, but does not require, states to combine target groups within one HCBS waiver. Prior to that change, a single section 1915(c) HCBS waiver could only serve one of the following three target groups: older adults, individuals with disabilities, or both; individuals with intellectual disabilities, developmental disabilities, or both; or individuals with mental illness. This change allows states to design a waiver that meets the needs of more than one target population. If a state chooses the option of more than one target group under a single waiver, the state “must assure CMS that it is able to meet the unique service needs of individuals in each target group, and that each individual in the waiver has equal access to all needed services.”16 The rule also establishes requirements for home and community-based settings under the 1915(c), 1915(i) and

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1915(k) Medicaid authorities, and person-centered planning requirements for Medicaid HCBS participants under 1915(c) and 1915(i).17

Because HCBS waivers are granted only for a limited number of slots at one time, waiver programs, by their nature, often have waiting lists. Because eligibility is based on the income of the consumer and not the family, most children and adults with disabilities meet income eligibility guidelines for the HCBS waiver, even if their families have income and resources.

Medicaid operates as a vendor payment program, which means that states pay providers, or vendors, directly. Although vendors must agree to accept Medicaid payment rates, payment for services such as respite can vary among states up to a maximum set by CMS. Respite care is the only service for which Medicaid will reimburse vendors for room and board expenses. While states may establish co-payments or deductibles for services, these charges cannot be levied on services provided to children under age 18.

In some but certainly not all states, HCBS providers may face stringent reporting requirements. To continue receiving a waiver, state Medicaid administrators must show CMS that waiver services cost no more than placement in a medical facility. States may also require vendors to show that without the services they provide, their clients would qualify for placement in a medical facility. Finally, the process of establishing rates for services can require significant cost accounting.

Federal funding agency:

Eligible entity:
State Medicaid Agency.

Points of contact:
A list of state Medicaid program websites is available from the National Medicaid Directors Association website. http://medicaiddirectors.org/about/medicaid-directors/

Related links:

References:


Combined 1915(b)/(c) Waivers

Authorizing legislation:
Title XIX, Sections 1915(b) and (c) of the Social Security Act.

Program purpose:
To enable states to provide a continuum of services to the aging or to people with disabilities. States use the §1915(b) authority to mandate managed care enrollment or limit provider contracting and §1915(c) authority to target eligibility for the program and provide home and community-based services. Thus, states can provide long-term care services in a managed care environment or use a limited pool of providers.

Funding:
All federal requirements for both §1915(b) and §1915(c) programs must be met. States must submit separate applications for each waiver type. For example, states must demonstrate cost neutrality in the §1915(c) waiver and cost-effectiveness in the §1915(b) waiver. States must also comply with the separate reporting requirements for each waiver. Renewal requests must be prepared separately and submitted at different points in time.

Activities supported by the funding:
All activities allowable under both §1915(b) and §1915(c) waiver programs may be included.

Respite connection:
As discussed in the section on §1915(b) waivers, these waivers may expand services to include respite; respite is specifically included under the §1915(c) authority.

Issues for consumers, providers, and advocates:
Combined waivers give states the option to propose inclusion of both traditional long-term care state plan services (e.g., home health, personal care, and institutional services) and nontraditional home and community-based services (e.g., homemaker and adult day health services and respite care) in their managed care programs.

§1915(b) waivers are renewed at 2-year intervals; §1915(c) waivers are approved for 5 years. Therefore, renewal requests on combined waivers must be prepared and submitted separately.

Federal funding agency:

Eligible entity:
State Medicaid Agency.

Points of contact:
A list of state Medicaid program websites is available from the National Association of Medicaid Directors website. http://medicaiddirectors.org/about/medicaid-directors/

Related links:
Additional Medicaid and Children’s Health Insurance Program Opportunities

The Patient Protection and Affordable Care Act, P.L. 111-148, enacted March 23, 2010, and the Health Care and Education Reconciliation Act of 2010, P.L. 111-152, enacted March 30, 2010, are together referred to as the Affordable Care Act (ACA). ACA included some important provisions that could potentially fund or support respite services for eligible individuals.

The following program was enacted under ACA:

- **Community First Choice (CFC) Medicaid State Plan Option** to enable individuals requiring an institutional level of care to receive attendant services and supports at home or in the community.

Other programs were originally enacted as part of the Deficit Reduction Act of 2005 and modified by ACA:

- **Section 1915(i) Medicaid State Plan Option for Home and Community-Based Services** to allow states to cover home and community-based services for Medicaid beneficiaries without a special waiver.
- **Money Follows the Person (MFP)** to help states increase home and community-based long-term care services by transitioning individuals out of institutions and reducing the reliance on institutional care for the elderly and individuals with disabilities by using savings from enhanced federal match for long-term care home and community based service systems development and sustainability.

The **Children’s Health Insurance Program (CHIP)** was first signed into law during the Clinton Administration. It was reauthorized by the Children’s Health Insurance Program Reauthorization Act of 2009 (CHIPRA), which was signed into law by President Barack Obama on February 4, 2009, and additional changes were made by ACA. The program was most recently reauthorized as part of the Medicare Access and CHIP Reauthorization Act of 2015. CHIP provides health care coverage for low-income children who do not qualify for Medicaid and who would otherwise be uninsured. States may elect to provide coverage to qualifying children by expanding their Medicaid programs or through a state program separate from Medicaid.

Each of these programs, demonstrations, or state plan options is described in this section.

For more information, visit the Medicaid.gov, Keeping America Healthy website.
Community First Choice (CFC) State Plan Option

Authorizing legislation:
Section 1915(k) of the Social Security Act, as amended by Section 2401 of the Patient Protection and Affordable Care Act, P.L. 111-148.

Program purpose:
To enable individuals requiring an institutional level of care to receive attendant services and supports at home or in the community.

Funding:
States will receive an enhanced federal match of 6% for included services.

Activities supported by the funding:
This option provides home and community-based attendant services and supports to assist the consumer in accomplishing activities of daily living, instrumental activities of daily living, and health-related tasks. This option helps consumers acquire, maintain, and enhance their daily living skills, trains the consumer on selecting, managing, and dismissing attendants, and establishes a backup system to ensure continuity of services.

Respite connection:
While respite is not specifically covered, family caregivers can receive breaks from caregiving while attendants are providing services.

Issues for consumers, providers, and advocates:
This state plan option became effective October 1, 2011. As of September 2015, five states have CMS approved 1915(k) State Plan Amendments (CA, MD, MT, OR, and TX).

Activities supported under this State Plan Option are more restricted than those allowed under the 1915(i) Home and Community-Based Services option. The following are definitions from Title XIX specific to this option:

“Activities of daily living” includes tasks such as eating, toileting, grooming, dressing, bathing, and transferring.

“Health-related tasks” means specific tasks related to the needs of an individual, which can be delegated or assigned by licensed health care professionals under state law to be performed by an attendant.

“Instrumental activities of daily living” includes (but is not limited to) meal planning and preparation; managing finances; shopping for food, clothing, and other essential items; performing essential household chores; communicating by phone or other media; and traveling around and participating in the community.

States must develop and implement this option in collaboration with a Development and Implementation Council that includes “a majority of members with disabilities, elderly individuals, and their representatives.”
Services must be offered on a statewide basis, without regard to the individual’s age or to the type, severity, or nature of the disability or the form of services required for the individual to lead an independent life. Services can be provided under an agency-provider model (within which individuals must maintain the ability to have a significant role in the selection and dismissal of providers of their choice), a self-directed model, or other models approved by CMS.

In 2014, CMS issued a final rule that establishes requirements for home and community-based settings under the 1915(c), 1915(i) and 1915(k) Medicaid authorities.\(^{18}\)

**Federal funding agency:**

**Eligible entity:**
State Medicaid Agency.

**Points of contact:**
A list of state Medicaid program websites is available from the National Association of Medicaid Directors website. [http://medicaiddirectors.org/about/medicaid-directors/](http://medicaiddirectors.org/about/medicaid-directors/)

**Related links:**
Centers for Medicare & Medicaid Services, *Community First Choice 1915(k)*


**References:**
Centers for Medicare & Medicaid Services. *Home & Community Based Services.*
[http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html](http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html)


[http://assets.aarp.org/rgcenter/ppi/ltc/fs192-hcbs.pdf](http://assets.aarp.org/rgcenter/ppi/ltc/fs192-hcbs.pdf)

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Section 1915(i) Medicaid State Plan Option for Home and Community-Based Services

Authorizing legislation:
Section 1915(i) of the Social Security Act, as amended by

- Section 6086 of the Deficit Reduction Act of 2005 (DRA); and
- Patient Protection and Affordable Care Act of 2010 (ACA).

Program purpose:
To allow states to cover home and community-based services (HCBS) for Medicaid beneficiaries without a special waiver and, thus, without having to demonstrate budget neutrality (compared to institutional care).

Activities supported by the funding:
As with §1915(c) HCBS waivers, states who take this option can offer a variety of medical and long-term services not previously covered by the state Medicaid program as long as these services are required to keep a person from being institutionalized. Services covered include case management, homemaker, home health aide, personal care, adult day health, habilitation, and respite care.

Respite connection:
Respite is specifically mentioned as a covered service in the federal regulations for this option [CFR 44.182 (c) (7)]. States are required to conduct an individual assessment of the needs of each individual determined to be eligible for the state option benefits.

Example: The purpose of Montana’s 1915(i) HCBS State Plan program is to provide mental health services to qualifying youth in the community setting. Services are provided through a wraparound service model that includes the youth and family and structured to provide the supports needed to maintain youth safely in their home and community. The state plan program defines respite care as the provision of supportive care to the youth when the unpaid persons normally providing day to day care for the youth will not be available to provide care. Respite care services may be provided only on a short term basis, such as part of a day, weekends, or vacation periods. Respite services may be provided in the youth’s home, another private residence or other community setting, excluding psychiatric residential treatment facilities. The provider of respite care must ensure that its employees providing respite care services meet specific qualifications.


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Issues for consumers, providers, and advocates:
Eligibility is determined by states. However, effective October 1, 2010, eligibility under this option was expanded to individuals with incomes up to 300% of the maximum Supplemental Security Income (SSI) payment. Unlike the HCBS waivers, under this option states cannot cap enrollment or maintain a waiting list.

In 2014, CMS issued a final rule that requires Section 1915(i) services be provided in a home and community-based setting, similar to Community First Choice state plan option services.20

The rule also establishes person-centered planning requirements for Medicaid HCBS participants under 1915(c) and 1915(i). CMS specifies that service planning for participants in Medicaid HCBS programs under section 1915(c) and 1915(i) of the Act must be developed through a person-centered planning process that addresses health and long-term services and support needs in a manner that reflects individual preferences and goals. This process must be directed by the individual with long-term support needs, and may include a representative whom the individual has freely chosen. The person-centered planning requirements under 1915(i) also stipulate that “if unpaid caregivers will be relied upon to implement any elements of the person-centered service plan” then a caregiver assessment must be conducted.

As of July 2015, 16 states (California, Colorado, Connecticut, Delaware, Florida, Idaho, Indiana, Iowa, Louisiana, Maryland, Michigan, Mississippi, Montana, Nevada, Oregon and Wisconsin) and the District of Columbia offered Section 1915(i) state plan benefits.21

Federal funding agency:

Eligible entity:
State Medicaid Agency.

Points of contact:
A list of state Medicaid program websites is available National Association of Medicaid Directors website.
http://medicaiddirectors.org/about/medicaid-directors/

Related links:
Centers for Medicare & Medicaid Services, Fact Sheet: Summary of Key Provisions of the Final Rule for 1915(i) Home and Community-Based Services (HCBS) State Plan Option

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Centers for Medicare and Medicaid Services, *Home and Community Based Services 1915(i).*

References:
Centers for Medicare & Medicaid Services. *Home & Community Based Services.*
http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html

Money Follows the Person (MFP) Demonstration Grants

Authorization:

Currently authorized through:
September 30, 2016.

Program purpose:
To help states increase home and community-based long-term care services by transitioning individuals out of institutions and reducing the reliance on institutional care for the elderly and individuals with disabilities. MFP uses savings from an enhanced federal match for long-term care (LTC) home and community-based services (HCBS) systems development and sustainability.

Beneficiaries:
Individuals in the state who, immediately before beginning participation in the MFP demonstration project, resided in an inpatient facility for at least 3 months; are receiving Medicaid benefits; and for whom a determination has been made that, but for the provision of home and community-based long-term care services, the individual would continue to require the level of care provided in an inpatient facility.

Funding:
In 2007, Centers for Medicare and Medicaid Services (CMS) awarded almost $1.5 billion in MFP competitive grants, with states proposing to transition more than 34,000 individuals out of institutional settings over the 5-year demonstration period. ACA extended and expanded funding for Medicaid Money Follows the Person Rebalancing Demonstration Programs through 2016. States receive an enhanced federal match for each Medicaid beneficiary transitioned to the community from an institution during the demonstration period.

Activities supported by the funding:
MFP demonstration grants pay for 1 year of community-based services for each person transitioned from an institution. Services that qualify for the MFP enhanced federal matching rate during a beneficiary’s MFP participation year are those waiver and state plan services that will continue once the individual’s MFP demonstration transition period has ended. The savings incurred by the state through the enhanced federal match, known as rebalancing funds, can be used to develop and/or sustain LTC HCBS systems and services.

Respite connection:
Respite programs for family caregivers are included in covered home and community-based services. Respite care means services provided to individuals unable to care for themselves, furnished on a short-term basis because of the absence of or need for relief for those persons normally providing care. MFP may not be claimed for the cost of room and board except when provided as part of respite care furnished in a facility approved by the state. Once individuals are living in the community, they can continue to access respite and other home and community-based services through waiver or state plan services.

In addition, rebalancing funds can be used to serve family caregivers of individuals who have been transitioned back into the community by providing respite and other caregiver supports.
Issues for consumers, providers, and advocates:
With the extension of the program through the ACA, additional states were able to start MFP demonstration projects, and the existing states were able to seamlessly transition into the next 5 years. As a result, by 2015, 44 States and the District of Columbia were receiving MFP grants. Additionally, CMS awarded funding for the Money Follows the Person (MFP) Tribal Initiative (TI) to five state grantees. The extension of the program also changed the definition of individuals eligible to participate in MFP. Individuals are now eligible for MFP after residing in an institution for more than 90 days instead of more than 6 months (as was formerly the case).

The limits in the supply and availability of a range of home and community-based services and supports, including respite, could impede the ability of some states to implement MFP. When states began to implement MFP, many grantees reported the need to increase the capacity of HCBS waiver programs in their state in order to meet the anticipated demand of MFP participants. This could present an opportunity for Lifespan Respite Programs or respite providers to partner with MFP programs to meet an anticipated increased respite demand.

Federal funding agency:

Eligible entity:
State Medicaid Agency or State Mental Health Agency.

Points of contact:
MFP and Home and Community-Based Waiver state contacts.

Related links:
Centers for Medicare and Medicaid, Money Follows the Person

Catalog of Federal Domestic Assistance: Money Follows the Person Rebalancing Demonstration.
https://www.cfda.gov/index?s=program&mode=form&tab=core&id=608884168116eecaef45984edbb48594

Example: The North Carolina Lifespan Respite Project partnered with the state Medicaid agency to use the state’s Money Follows the Person Rebalancing Fund to support family caregiver peer support and respite volunteer models. Those eligible were family caregivers who had assumed more caregiving responsibilities for an individual transitioning back to their home/community or individuals at risk of being admitted into a long-term care facility.

References:


Children’s Health Insurance Program

Authorizing legislation:
Title XXI of the Social Security Act, as amended by

- Children’s Health Insurance Program Reauthorization Act of 2009 (CHIPRA), P.L. 111-3, and
- Patient Protection and Affordable Care Act of 2010 (ACA), P.L. 111-148.

Currently authorized through:
September 2019, but funded only through September 30, 2017.

Program purpose:
To provide health care coverage for low-income children who do not qualify for Medicaid and would otherwise be uninsured. States may elect to provide coverage to qualifying children by expanding their Medicaid programs or through a state program separate from Medicaid. States may elect to cover pregnant women and currently five states offer this coverage.

Beneficiaries:
Targeted uninsured low-income children up to age 19 who have been determined eligible by the state for child health assistance under their state plan are children whose family income exceeds the Medicaid-applicable income level but does not exceed 50 percentage points above the Medicaid applicable income level and are not found to be eligible for medical assistance under Title XIX or covered under a group health plan or under health insurance coverage. States have broad flexibility to set their CHIP income eligibility levels. Most states cover children in families up to or above 200 percent of the federal poverty level. In federal FY 2013, 8 million children were enrolled in coverage funded by CHIP.

Funding:
Federal and state governments jointly finance the CHIP, although the federal government assumes a larger share of the financing with a matching rate ranging from 65 to 81 percent. Unlike Medicaid, CHIP funds are capped for each state. This capped funding is distributed through state-specific allotments determined by a formula to account for the state’s actual use of CHIP funds, adjusted for health care inflation and child population growth.

Activities supported by the funding:
Within broad federal guidelines, each state determines the design of its program, eligibility groups, benefit packages, payment levels for coverage, and administrative and operating procedures. Categories of basic services include inpatient and outpatient hospital care, doctor’s care, laboratory and x-ray services, and well-child pediatric care, including immunizations. Plans may also cover prescription drugs and mental health, vision, and hearing services. States can choose health benefits coverage, but it must be equivalent to those offered under: (1) the standard Blue cross/Blue Shield preferred provider option service plan offered to federal employees; (2) a health plan available to a state’s public employees; or (3) the HMO within the state that has the highest commercial enrollment (excluding Medicaid enrollment).

Respite connection:
The original statute specifically states that nothing prevents a state “from providing coverage of benefits that are not within a category of services.”
**Issues for consumers, providers, and advocates:**
Both eligibility for CHIP and covered services are determined by each state, within broad federal guidelines. States are required to cover medically necessary services but rarely have expanded CHIP coverage to personal care, family support, or respite.

**Federal funding agency:**

**Eligible entity:**
State CHIP programs can be run by a State Medicaid Agency or by another state entity as a separate child health insurance program.

**Points of contact:**
Links to state CHIP websites are available on the federal government’s Connecting Kids to Coverage website.  [http://www.insurekidsnow.gov/state/index.html](http://www.insurekidsnow.gov/state/index.html)

**Related links:**
Catalog of Federal Domestic Assistance: Children’s Health Insurance Program.  [https://www.cfda.gov/index?s=program&mode=form&tab=core&id=6a755cd785c483b5b892708adaecf998](https://www.cfda.gov/index?s=program&mode=form&tab=core&id=6a755cd785c483b5b892708adaecf998)

Center for Medicaid and Medicaid Services, Medicaid.gov, *Child Health Insurance Program*  

Center for Medicaid and Medicaid Services, *CHIP State Plan Activity as of May 1, 2015*  


**References:**