Global Genes®
RARE Toolkits

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Understanding and Navigating Medicaid

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Global Genes is a 501(c)(3) non-profit organization dedicated to eliminating the burdens and challenges of rare diseases for patients and families globally. In pursuit of our mission we connect, empower, and inspire the rare disease community to stand up, stand out, and become more effective on their own behalf—helping to spur innovation, meet essential needs, build capacity and knowledge, and drive progress within and across rare diseases. We serve the more than 400 million people around the globe and nearly 1 in 10 Americans affected by rare diseases. If you or someone you love has a rare disease or are searching for a diagnosis, contact Global Genes at 949-248-RARE or visit our resource hub at www.globalgenes.org.

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Acknowledgments

Lauren Alford
Senior Marketing Communications Director
Global Genes

Nikki Berry
Senior Brand Manager
Global Genes

Alex Cameron
Digital Marketing Manager
Global Genes

Hira Chowdhary, MPH, MS
Senior Program Manager, Engagement Programs
Global Genes

Marie Daghlian
Copy Editor
Global Genes

Craig Martin
Chief Executive Officer
Global Genes

Pam Rattananont, MPH
Vice President, Development and Marketing
Global Genes

Christian Rubio
VIce President, Strategic Advancement
Global Genes

Contributors

Michael Spiegler
Vice President of Patient Services and Kidney Disease Education
American Kidney Fund
kidneyfund.org

Kathleen McGlone Campbell, SBL Adv. Cert, MEd
Rare Mom, Teacher, Science Lab Coordinator, and STEM Educator

Amy Aikins
Director, Government and Social Programs, Little Hercules Foundation
littleherculesfoundation.org

Max Bronstein
Principal, MGB Consulting
Founder, Journal of Science Policy & Governance
sciencepolicyjournal.org

Thistle Editorial LLC
thistleeditorial.com

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Introduction

What is Medicaid?

Medicaid is a joint federal and state health insurance program that helps people with low incomes, people with disabilities, and people receiving Supplemental Security Income (SSI) pay for health care. It is the largest health insurer in the United States and provides health coverage for one in five Americans.[1]

Eligibility criteria and benefits can be markedly different throughout the country, as states devise their own Medicaid programs. Although states must adhere to minimum standards set by the federal government, they are given substantial latitude with regard to eligibility for optional Medicaid programs and coverage of treatments. Complicating things further, Medicaid may be managed by the Department of Public Health in one state, the Department of Community Health in another, and the Department of Human Services in another state. In other words, instead of one Medicaid program, there are more than 50 Medicaid plans in the United States (Washington, D.C. and U.S. territories, such as Puerto Rico, have their own Medicaid programs).

The goal of this toolkit is to provide information and resources to help you determine whether you would benefit from Medicaid coverage, identify different pathways for people with rare disease, and learn about programs of interest to people with rare disease.

This toolkit focuses on the following topics:

1. Medicaid eligibility
2. Different pathways to eligibility
3. Programs and benefits
4. **Waiver** programs
5. **Drug utilization review**

Medicaid Overview

The Social Security Act of 1965 led to the creation of Medicaid to provide health insurance for people with low incomes.[2] Coverage was extended to children and pregnant women in the 1980s-1990s.[3] The extent of coverage varies by state. The federal government provides guidelines for Medicaid programs and approves each state's Medicaid plan. However, Medicaid is administered by states, and each state decides what to call its Medicaid program. While many states call the program Medicaid, others have created unique names. For instance, it's Medi-Cal in California, KanCare in Kansas, and MO HealthNet in Missouri.

Medicaid Facts[3]*

97 million people have Medicaid
Most beneficiaries are children
9 million people with disabilities
~10 million have dual coverage with Medicare and Medicaid

**Based on fiscal year 2018.*

The majority of states use a **managed care organization** (MCO) to help control costs. MCOs take a value-based approach to healthcare to save money. This can mean restrictions on access to care or treatments. Under this arrangement, the state Medicaid program pays the MCO a fee for each Medicaid **beneficiary** enrolled in the MCO. Others use a fee-for-service payment model, which means the state's Medicaid program pays the

physician or healthcare provider (HCP) directly. In a fee-for-service model, each state sets its own reimbursement rate for physicians who accept Medicaid patients. Some states use an MCO for some services and a fee-for-service payment model for other services.[4] Medicaid typically pays lower rates to doctors and other HCPs than Medicare and private insurance, which is why some HCPs do not treat patients with Medicaid coverage.

States and the federal government jointly fund Medicaid programs. At a minimum, the federal government matches every $1 that a state contributes for costs of federally mandated healthcare services. This is known as the **Federal Medical Assistance Percentage** (FMAP), which reflects a state's average per-capita income compared to the national average. Less wealthy states receive a higher amount for every $1 they spend on Medicaid.[5] Of note, waiver programs receive a lower FMAP compared to benefits that have been incorporated into a state's overall Medicaid benefits.[6]

Am I Eligible?

Medicaid eligibility is primarily based on income, and criteria are denoted as a percentage of the *Federal Poverty Level* (FPL). The Census Bureau updates the FPL annually. For many people, income eligibility is based on Modified Adjustable Gross Income (MAGI).[7]

The Patient Protection and Affordable Care Act (ACA) gave states the option to expand Medicaid coverage by increasing the percentage of FPL used in eligibility requirements; 35 states and Washington, D.C. have used this expansion to enable millions of Americans to get access to health insurance.[3] As part of the ACA, the federal government committed to pay 100% of coverage for individuals under the expanded Medicaid eligibility program for three years and then 90 percent of program costs.[9] In addition, states that adopted the new ACA coverage essentially created a new category of eligible people who previously would not be covered under Medicaid in the past: working-age adults without disabilities and without children.[1]

The Centers for Medicare and Medicaid Services (CMS), a federal agency within the Department of Health and Human Services, provides an *overview of states' Medicaid programs*. Each overview shows eligibility criteria for the state as well as waiver programs. CMS also provides *links* to the department in each state government that administers Medicaid. The Institute for Medicaid Innovation also provides *fact sheets* on each state's Medicaid program.

Modified Adjustable Gross Income (MAGI)

Because states have different tax codes, MAGI takes a nationwide approach to income.[7]

- MAGI is not a line on your tax return. However, for most people, it will approximate what is shown as adjusted gross income on a federal tax return.
- MAGI does not include Supplemental Security Income. Child support from a non-custodial parent or alimony are not *included in MAGI*.
- MAGI does include tax-exempt interest earned, non-taxable benefits from Social Security, and untaxed foreign income.[8]

General Eligibility Criteria

To receive federal matching dollars for their own contribution to Medicaid, states are required to cover the following groups of people:[3]

- Children younger than 19 years of age whose family income is less than 138% of FPL
- Pregnant women with income less than 138% of FPL
- Some parents or caretakers with low income
- Senior citizens who receive Supplemental Security Income (SSI)
- People with significant disabilities who receive SSI

To apply for Medicaid:

- Apply at the *Health Insurance Marketplace*
- Contact your state's Medicaid department
- Go to the Social Services office in your county
- Apply for *SSI*

However, the federal government permits some caveats to the above criteria. The income threshold of less than 138 percent of FPL was mandated in the ACA. With state governments experiencing budget shortfalls, states were allowed to restrict the income for Medicaid eligibility.[5] Most states now use the income threshold of 133 percent of FPL for working adults.

For children, the parental income threshold varies by state, and sometimes by the child's age. For instance, in Massachusetts, parental income cannot exceed 200 percent of FPL for children up to the age of one. Thereafter, parental income cannot exceed 150 percent of FPL.[10] In Florida, the parents' income cannot exceed 206 percent of FPL for children to the age of one, 140 percent for children aged 1-5 years, and 133 percent for children aged 6-18 years.[10] The federal government's Medicaid webpage provides *state-specific income eligibility thresholds* for children, pregnant women, adults who are caretakers, and ACA-permitted new beneficiaries.[10] Senior citizens are eligible for Medicare. Those with low income may also be eligible for Medicaid or for Medicare Savings Programs to help with the costs of Medicare. Those who have both Medicare and Medicaid are known as dual eligible. People who receive SSI can have dual Medicare-Medicaid coverage, which can help reduce out-of-pocket medical expenses.[11]

PRO TIP 1: MEDICAID "NEED TO KNOW"

- Medicaid coverage doesn't follow you if you move to another state; you'll have to reapply in the new state.
- You have to provide proof that you live in the state; if your home situation is uncertain, consider using the address of a trusted family member.
- You have to provide documents to prove your income and assets, such as documents (W-2s) and bank statements.
- Organize recent medical bills; Medicaid may retroactively provide coverage for recent doctor visits and treatments.
- If you had Medicaid as a child, you may have different eligibility requirements as an adult.
- Because Medicaid is a program for people with low income, your eligibility can change over the course of a year if your income increases.

With private insurance, most people can only apply for insurance during "open enrollment periods" at specific times of the year. For Medicaid, there's no enrollment period. You can apply at any time, online or in person. The majority of applications are processed within seven days. However, about 15 percent of applications take more than 45 days to process.[12]

PRO TIP 2: APPLY FOR MEDICAID AND SSI AT THE SAME TIME

States are required to offer Medicaid to children who qualify for SSI. If your child has significant disabilities, you might want to apply for SSI and Medicaid at the same time although you will have to fill out separate applications. Even if you are rejected for SSI, it can be worth the time. For instance, if you are applying for Medicaid for your child with a rare disease, you might need the SSI denial in order to complete enrollment for your child in Medicaid. (Only about 15 percent of children who are enrolled in Medicaid also receive SSI benefits).13 Other groups that can *apply for SSI* include senior citizens with low incomes and adults with a disability or who are blind.

TEFRA and the Katie Beckett Waiver

Despite family income exceeding Medicaid eligibility limits, children aged younger than 19 years with significant disabilities and living at home may be eligible for Medicaid through a provision of the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA). TEFRA adoption is not mandated, which means that states are not required to implement TEFRA in their Medicaid programs.[10] However, all states offer a pathway for children with complex medical needs living at home. This is sometimes called a TEFRA waiver or the Katie Beckett Waiver. In some states, this is an actual waiver program; in others, it is a distinct Medicaid eligibility category. It is important to note that waiver programs specify what populations they serve, and have different requirements.

Who is Katie Beckett?

As an infant, Katie Beckett had viral encephalitis and went into a coma. She developed partial paralysis that required her to be placed on a ventilator for much of the day. Most of her first three years were in the hospital. When she was older, doctors agreed that she could live at home with the necessary support, such as a ventilator.[14] However, Medicaid would not provide reimbursement for home-based care. That meant that parents would have to use their own financial resources to accommodate having their child with medical complexity at home. However, if the child had been in an institution for 30 days, Medicaid would consider only the child's income and assets for coverage eligibility. Thus, parents were faced with the choice of paying out of pocket for home-based care or having to institutionalize their child for 30 days in order to receive Medicaid coverage.[10]

Katie's mother embarked on advocacy to get Medicaid to cover Katie's home-based care. Her efforts reached President Reagan's attention who waived the Medicaid restriction for Katie.[15] The Katie Beckett provision included in TEFRA, which was passed the following year, gave state Medicaid programs the option of not including parental income when determining eligibility for care that would otherwise be covered by Medicaid.[10]

The ease of (or difficulty with) getting Medicaid coverage under this pathway depends on whether the state has incorporated the eligibility into its state Medicaid program through a state plan amendment (SPA) or through a waiver program. For states that have filed an SPA for TEFRA, the criteria outlined in the SPA determine whether a child with complex medical needs can access Medicaid through this pathway.

Most states use a waiver to the existing Medicaid eligibility requirements for children with significant disabilities. Using a waiver program allows states to cap the number of children who can get access to Medicaid through this pathway. If a state reaches its limit for the waiver program, new applicants are typically put on waiting lists to receive Medicaid coverage.[11]

States that have filed SPAs to expand their Medicaid eligibility to children with significant disabilities regardless of the parents' income are Alaska, Delaware, Georgia, Idaho, Iowa, Maine, Massachusetts, Minnesota, Mississippi, Nevada, New Hampshire, Oklahoma, South Carolina, South Dakota, Vermont, and West Virginia. Washington, D.C. also has an SPA for its Medicaid program. Colorado, New York, and Rhode Island use both an SPA and a waiver program to provide Medicaid coverage for these children.[11] Tennessee was the last state to create a Katie Beckett waiver program for children with significant disabilities. Its program was approved on November 2, 2020.[16]

Under TEFRA or a Katie Beckett waiver, the financial eligibility is based on the child's rather than the parents' income. The child's income cannot exceed 300% of SSI and the child cannot have assets above $2,000, which is generally consistent among states. The type of disability covered for this eligibility pathway may vary by state. In general, the child must meet *Social Security's medical disability requirements* and qualify for institutional care. **Premiums** for Medicaid may be slightly higher for children covered under a TEFRA or a Katie Beckett provision.[11]

PRO TIP 3: FIND A MENTOR

Medicaid is complex because it is different in every state and states don't have the same waiver programs or benefits.

While you can contact the Medicaid department in your state or visit the Social Services office in your county, people with rare disease often find out about Medicaid programs from other people with a rare disorder. If your rare disease is large enough to have a foundation or a nonprofit advocacy group, look for information on Medicaid on those sites. Look for a support group where you can connect with others. A mentor can alert you to special Medicaid programs in your state and let you know how to apply.

State Plan Amendment or Waiver: Does It Matter?

An SPA means that the state has formalized the criteria as part of its eligibility. Once approved by the federal Department of Health and Human Services, the new criteria are part of the state's Medicaid program. With this approach, the state receives matching federal funds and there are no limitations on the number of people who can use that eligibility criteria.

However, when a state chooses to use a waiver program to allow exceptions to eligibility or services, the state has a limit on matching federal funds it can receive. States that use this approach can restrict the number of people who can access Medicaid through the waiver eligibility.[11,17]

If your state has a waiver program, the state may require you to provide a substantial amount of documentation to demonstrate that you meet the criteria for the waiver. In addition, some states outsource this function to another department or organization, which might have its own requirements, such as a mandated class about the waiver program.

Medically Needy

States can establish a medically needy pathway for people who have a higher income than the general income eligibility criteria for Medicaid (138 percent of FPL). Under this pathway, a person's medical expenses, not just income, is a factor in determining Medicaid coverage.

Thirty-four states and Washington, D.C have established medically needy programs for children and pregnant women, and 32 states also offer medically needy coverage for senior citizens and working adults with significant disabilities. Twenty-six states have extended medically needy coverage to low-income parents. The income and asset criteria for medically needy programs varies by state.[11] You have to contact your state's Medicaid program to see if a medically needy program is available in your state.

Most states with a medically needy program allow people to "spend down" to reach the medically needy income criteria. States choose a period of 1-6 months during which time the applicant must have enough medical expenses to lower their income to the state's medically needy income threshold. Thereafter, Medicaid will cover healthcare expenses.[11]

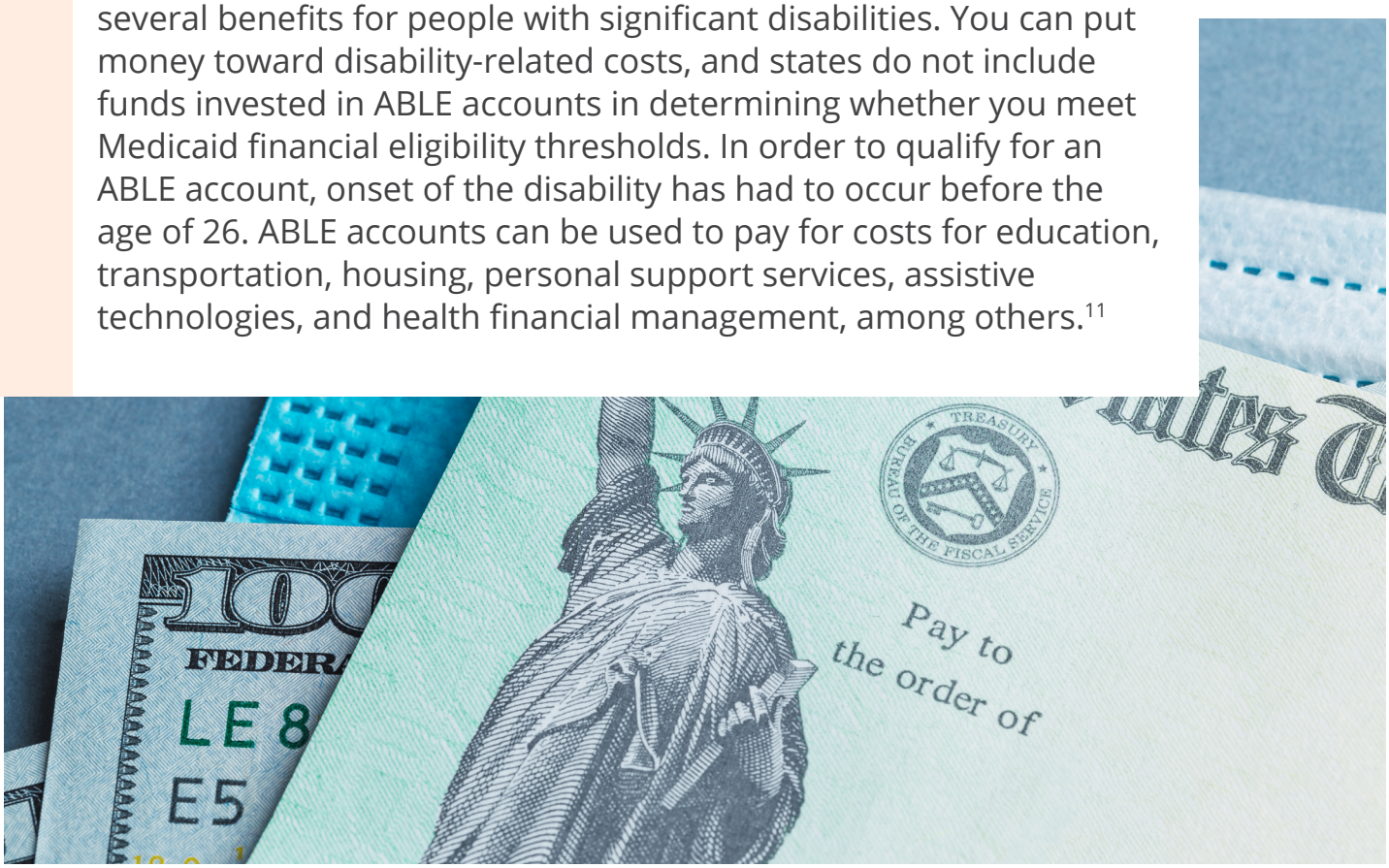
Buying In

Working adults with disabilities can "buy into" Medicaid in 45 states. This allows for people with moderate incomes to get health insurance, which may be cost prohibitive on a health insurance exchange or through an employer-sponsored healthcare plan. In addition, a state's Medicaid program may cover services needed by people with disabilities that private insurance does not. However, most states require people who "buy into" Medicaid to pay a premium using a sliding scale based on income. Seventeen states have a flat fee, and eight use a percentage of gross or net income to determine the premium amount.[11]

Five states—Colorado, Iowa, Louisiana, North Dakota, and Texas—use a provision from the Family Opportunity Act (FOA) to offer Medicaid coverage for children with disabilities; Massachusetts offers this as a waiver program. To qualify for the FOA provision, children have to meet criteria for SSI medical disability, and parental income can be up to 300 percent of FPL. States also may charge a premium for Medicaid coverage of up to 5 percent of parental gross income.[13]

PRO TIP 4: CREATE AN ABLE ACCOUNT TO BECOME MEDICAID ELIGIBLE

Creating an Achieving a Better Life Experience (ABLE) account has several benefits for people with significant disabilities. You can put money toward disability-related costs, and states do not include funds invested in ABLE accounts in determining whether you meet Medicaid financial eligibility thresholds. In order to qualify for an ABLE account, onset of the disability has had to occur before the age of 26. ABLE accounts can be used to pay for costs for education, transportation, housing, personal support services, assistive technologies, and health financial management, among others.[11]



Children's Health Insurance Program (CHIP)

CHIP, a distinct program within Medicaid, is another way to access health coverage for children. CHIP was created by a provision in the Balanced Budget Act of 1997. CHIP is funded through a block grant from the federal government, which covers a certain period of time and must be renewed by Congress. States have to make up any shortfall between the grant received by the federal government and CHIP program costs.[18]

To qualify for CHIP, children must be younger than 19 years and not have health insurance from another source. *Eligibility* also is based on parental income. CHIP is for moderate-income families. If the parents' income is too high to qualify for Medicaid, the child may be eligible for CHIP. The qualification rules and what the plans cover vary from state to state.[2,7] Each state can *name* its program. Many states use CHIP; others have created unique names.

In some states, CHIP operates very similarly to the state's Medicaid program. In others, the programs are administered and operated differently. There is no enrollment period for CHIP. You can apply at any time. The majority of states *process applications* within seven days.[12] However, some states have a *waiting period* of up to 90 days before coverage begins.

In all states, CHIP covers routine check-ups, immunizations, doctor visits, prescriptions, dental and vision care, inpatient and outpatient hospital care, laboratory and X-ray services, and emergency room services.

Congress let CHIP funding expire in fiscal year 2018, which ended September 30, 2017. Funding was renewed through the Healthy Kids Act, which was signed into law in January 2018. The Healthy Kids Act extended CHIP funding through September 30, 2023 but states had the option to make eligibility more restrictive starting in 2020.[18]

Some states allow parents to buy into CHIP coverage. The Healthy Kids Act permitted states to offer CHIP without the essential health benefits specified in the ACA. In addition, the law permits states to charge parents the full cost of the health insurance, which could make CHIP financially out of reach for some families.[18]

Appeals[19]

If your application for Medicaid or CHIP is rejected, you have the right to appeal the decision. However, it may be faster to request a reversal of the decision.

If rejected, you will receive written notification for the reasons why coverage was denied. The notice should also include how to appeal the decision.

The formal appeal process varies by state but involves a hearing. You have to request a hearing, and it's best to do this in writing. Often, you have to file this request within 10 days of the date shown on the denial notice.

Although the hearing does not take place in a courthouse, it is similar to a court case. You can have an attorney represent you, you can present evidence, and you can ask the Medicaid or CHIP employee questions.

Medicaid Benefits, Costs, and Renewals

The federal government requires that states cover certain mandatory benefits for Medicaid beneficiaries and gives states broad latitude to offer additional benefits, which can be specified in a state's SPA or permitted through a waiver program. In general, the required benefits reflect the needs of the Medicaid population. Medicaid covers prenatal care and delivery costs for pregnant women, child development care for young children (immunizations, dental, vision, etc.), and assistance with Medicare premiums and copays as well as nursing home costs for senior citizens.[1] Medicaid often bridges gaps in coverage for children with significant disabilities and private insurance; it also may offset private insurance copays.[17] State Medicaid programs are also required to limit out-of-pocket expenses for beneficiaries.[1]

Mandatory Benefits

Mandatory benefits include physician fees, inpatient and outpatient hospital services, nursing facilities, laboratory tests and X-rays, home health services, family planning, nurse-midwife services, freestanding birthing centers, and pediatric and family nurse practitioners, among others. Children are covered for additional medical, dental, and vision benefits.[20]

Medicaid Benefits by State

The Kaiser Family Foundation, a nonprofit organization that focuses on healthcare policy analysis, provides data tables on *Medicaid benefits*. You can click on a benefit type, such as Physical Therapy, and a table shows whether each state provides coverage, requires a copayment, or imposes limits. Don't bypass the footnotes; they can provide useful additional information.

Basic home health services are an important mandatory benefit for older adults and people with significant disabilities. Nursing facilities are covered for adults, which is often important for elderly Medicaid beneficiaries.[10] States must also offer Medicare Savings Programs for elderly patients who also qualify for Medicaid.

This can help senior citizens with low incomes pay for Medicare premiums, deductibles, and out-of-pocket expenses.[11]

Adults who received Medicaid coverage through the ACA expanded criteria also must receive coverage for the 10 essential health benefits outlined in the ACA. These include preventive health services, mental health, and substance abuse.[1]

Even though benefits are mandatory, the scope and duration of coverage can vary by state. For instance, states can limit the number of hospitalization days covered by Medicaid. States can also limit coverage of a mandatory benefit by having a narrow definition of "medically necessary."[4]

The Centers for Disease Control Prevention (CDC) has compiled a list of *early intervention programs by state*. This resource includes the name of the program, which varies by state, and contact information.

Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) is a mandatory program for children and young adults (up to the age of 21) who are enrolled in Medicaid. Each state can decide what to call the program. The aim is to prevent, detect, and treat medical, dental, developmental, and mental health conditions. Child immunizations, laboratory tests, and screening for mental, behavioral, dental, vision, and hearing disorders are covered in this program.[21] In addition, states must offer specific *early intervention programs* for children through the age of three.

Optional Benefits

States can also elect to provide coverage for other services. If a state chooses to offer the service as an optional benefit, the service must be available to all beneficiaries within a Medicaid eligibility category and must be offered statewide. These are called comparability and statewide requirements that are mandated by the federal government.[10]

Coverage of prescription drugs is an optional benefit for Medicaid programs. Fortunately, all states do provide coverage for pharmaceutical treatments.[3] In general, copayments are low. However, states can impose limitations on prescription drug benefits, including **prior authorizations**, **step therapy**, and narrow use criteria, which can make it difficult to access needed treatments for people with rare disease (see "Drug Utilization Review Boards" for additional information).

Table 1. Medicaid Optional Benefits[22]*

Benefit	# of States Offering Benefit~	Copayments Required	States Imposing Restrictions^
Prescription Drugs	51	36	32
Over-the Counter Products	42	27	30
Physical Therapy	40	13	24
Occupational Therapy	39	13	23
Speech, Hearing, Language Disorders	37	12	21
Dentures	31	7	27
Eyeglasses	33	11	28
Hearing Aids	28	9	24
Prosthetic & Orthotic	45	13	30
Mental Health & Substance Use	43	8	24
Personal Care Services	34	2	20
Self-Directed Personal Assistance Services	21	1	17
Case Management	19	2	8
Targeted Case Management	36	2	17
Ambulance	46	6	10

**Fiscal 2018 data latest available; only includes data on Medicaid programs for adults.*
~Washington, D.C. included in the data.
^Additional restrictions may be imposed by Drug Utilization Review boards or waiver programs.

Prescription Drug Benefit

Although considered an optional benefit from the federal government, prescription drug coverage is offered by all state Medicaid programs. Medicaid does not require all beneficiaries to make copayments for medications. For those who have a prescription drug co-payment, the rate is very low ($1-$8).[23] Some states may cap the number of prescription drugs that are covered for a Medicaid enrollee each month. Most states permit an override to this benefit limitation.[24]

One reason that Medicaid can have low copayments for prescription drugs is the *Medicaid Drug Rebate Program* with states. Mandated by the federal Department of HHS, the drug rebate program requires drug manufacturers give Medicaid programs the lowest available price for treatments. In exchange, state Medicaid programs

agree to cover treatments that have received approval from the Food and Drug Administration (FDA). Under an arrangement with the federal government, states are required to give the federal government part of the rebate funds.[25] The majority of states (46) negotiate separate, additional rebate programs with drug manufacturers.[24]

Most state Medicaid programs outsource the prescription drug benefit to a third party, either to the MCOs managing Medicaid enrollees for the state or to a **pharmacy benefit manager** (PBM). States can opt to have the MCO or PBM manage all prescription drugs for Medicaid enrollees or to oversee the coverage for select treatments on its own. The latter is known as "carving out" and allows the state to retain the drug rebate from the manufacturer.[25]

Prescription Drug Cost Containment Strategies

The prescription drug benefit is a costly expense for Medicaid programs. Medicaid costs for prescription drugs rose 48 percent in 2014-2017, increasing overall Medicaid costs.[25] Because of growing use of pharmaceutical treatments for an array of diseases and conditions, state Medicaid programs have looked to control costs related to prescription drug coverage. These cost containment efforts create barriers to the use of a drug or treatment to limit use and, thus, lower prescription drug spending in the state's Medicaid program. States control drug benefit costs in a number of ways, as discussed below.[26]

Preferred Drug Lists (PDLs)

The majority of states (46) use a PDL, which is the most common way to control utilization of a medication, in their fee-for-service enrollees. PDLs are used to encourage use of generic drugs and direct healthcare providers to prescribe any medications for which the state has an additional rebate deal with the drug manufacturer. If the state contracts with MCOs, the MCOs typically have their own PDLs, which can differ from the Medicaid fee-for-service PDL.[24]

States use different entities to create and update PDLs. Most states (29) use a Pharmacy and Therapeutics (P&T) Committee to oversee the PDL, seven states have a department/ agency in their Medicaid program manage the PDL, and six states use a Drug Utilization Review (DUR) board

(P&T Committees and DUR boards are discussed in more detail below). Hawaii, New Jersey, New Mexico, and South Dakota do not use PDLs for their fee-for-service beneficiaries.[24]

Who Oversees Medicaid's Prescription Drug Cost Containment Strategies?

As with other aspects of Medicaid, each state can determine how to structure its cost containment measures. Oklahoma authorizes a Drug Utilization Review (DUR) board to decide on PDLs, step therapy criteria, and prior authorization criteria. Florida assigns a Pharmacy and Therapeutics (P&T) committee to oversee changes to PDLs, a DUR board to establish step therapy criteria, and a Medicaid agency to handle PAs. Missouri has a Medicaid agency handle all prescription drug cost containment efforts.24

This is a good resource for finding updates on Medicaid programs and policies. It routinely surveys states about how they manage Medicaid benefits, including prescription drug coverage.

Prior Authorization (PA)

PA is a common way for states to limit use of a certain medication or drug class. PAs require a physician or nurse practitioner to contact Medicaid or its MCO(s) to receive approval for prescribing the medication. PA is typically required for prescription drugs not on the Medicaid or MCO's PDL. In this way, Medicaid encourages healthcare providers to prescribe lower-priced medications on the PDL.[24]

All states use PAs for some prescription drugs in their Medicaid fee-for-service programs. When states contract with MCOs to provide services to their Medicaid population, most require the MCOs to follow the state's PA criteria for fee-for-service recipients. State Medicaid programs and their MCOs must follow two things mandated by the federal government:

1. Respond to PA requests within 24 hours and
2. In an emergency situation, states must authorize a three-day supply of the medication.[26]

Despite these requirements, it can be difficult for patients with rare disease to access new treatments (see "Orphan Drugs" below).

Most states require PA for recently approved treatments for a variety of reasons, including:

- The therapy is in a class of drugs that is already on a PDL (so an alternative, lower-cost medication may be available)
- The cost of the medication is above a certain price
- A Drug Utilization Review board or a Pharmacy and Therapeutics Committee has not yet assessed whether the new treatment should be made available to Medicaid enrollees.[24]

"Step therapy" is often used in PA algorithms (decision trees). Step therapy requires that you begin treatment with one therapy, usually a lower-priced generic drug. You have to "fail" that treatment before you're allowed to be prescribed another treatment. Failing means that your symptoms don't improve, or your body doesn't respond to the drug. (Sometimes step therapy is referred to as Fail First.) Step therapy is used by 45 states.[24]

Newer, specialty treatments are often expensive. Thus, it's common for states to require PA for specialty treatments. Some states have placed restrictions on Medicaid's ability to require PAs for certain therapies such as those for HIV, cancer, and mental health.[24]

PRO TIP 5: GET HELP WITH PAS

When states mandate a PA for a particular treatment, it makes it more difficult for you to get access to the therapy. Your doctor is the first champion on your behalf, as he or she will need to interact with Medicaid or Medicaid's MCO to explain why you need the treatment. In addition, you can reach out to the Patient Assistance Program at the manufacturer for the treatment. Join patient forums for your rare disease so that you can learn about additional resources or tips from others who have your rare disease.

Drug Utilization Review (DUR)

DURs are federally mandated so all state Medicaid programs have a DUR board. DUR has two parts: real-time monitoring of the use of prescription drugs, known as "prospective," and periodic review of the use of the treatment in the past, known as "retrospective." States must provide CMS an annual report on DUR showing prescribing trends, program operations, DUR decisions, and any cost savings from DUR decisions.[26] MCOs who oversee Medicaid programs may have a separate DUR board.[24]

DUR boards have a lot of power and can significantly affect the lives of people in Medicaid by limiting use of an intervention. States can specify other activities it wants its DUR board to handle. For instance, in six states, the DUR board decides which new drugs should be placed on Medicaid's PDL. The DUR board sets step therapy criteria in 14 states and prior authorization in 15 states.[24]

DUR boards can set strict criteria for the use of a new treatment. For instance, sometimes they only let people who have traits that match those of patients enrolled in the clinical trial for the treatment. Thus, a patient who otherwise meets the criteria for a new treatment but isn't in a wheelchair (when most in the clinical trial needed wheelchairs) may be denied Medicaid coverage for the treatment. DUR boards may include age criteria, authorizing use for people younger than 18 years but denying coverage for people 19 years and older. DUR boards may require

step therapy before the treatment is authorized for coverage.[27]

Pharmacy and Therapeutics (P&T) Committees

The federal government does not require state Medicaid programs to have a P&T committee. However, a majority of states use them. P&T committees oversee the PDL in 39 states, decide step therapy criteria in 12 states, and establish PA criteria in 9 states.[24]

DUR and P&T Schedules by State

Patients Rising Now, a patient advocacy group, has aggregated information on states' DUR boards and P&T committees (if a state has the latter). In addition to providing links to appropriate state websites, this *resource* indicates the frequency of meetings (e.g., quarterly, semi-annually, etc.) and includes a link to board and committee schedules. Physicians, nurses, and pharmacists often serve on DUR boards and P&T committees. However, a state may also allow people who don't have medical knowledge.[27]

Orphan Drugs

Treatments created for diseases that affect less than 200,000 people in the United States are called orphan drugs. Orphan drugs are often expensive as many have been developed by years of research and development and/or have used new technologies to identify how a rare disease can be treated effectively.

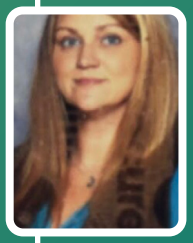
How states evaluate orphan drugs for inclusion in Medicaid prescription drug coverage varies. In 17 states, a department/agency within the state's Medicaid program makes decisions for coverage, 12 states rely on DUR boards, and 10 use a P&T committee.[24]

It usually takes three months for a DUR board or P&T committee to decide on a policy for use of a new therapy. However, in some cases, it can take more than a year to decide on coverage policy for new, breakthrough therapies.[26]

Case Managers

Not all states provide reimbursement for case managers, whereas others require case management. In some states, you could have more than one case manager, as there are several different types of case managers. Some case managers coordinate care among primary care physicians (PCPs) and specialists and make sure that comprehensive care is being provided. Sometimes you are assigned a case manager. Sometimes you are allowed to choose your own case manager. Children with significant disabilities and/or medical complexity are more likely to case managers than other Medicaid beneficiary groups.

Kate McGlone, M.Ed., lives in New York and has two children with a rare disease. She offers her thoughts on case managers:



"I was told by Medicaid that I needed to find a care manager. Medicaid in my state has a list of approved care managers. I made a few phone calls but every care manager that I called told me I was on a waiting list for three to six months so I went to the first one that would take my case quickly. If someone can take your case quickly, that should tell you that that care manager isn't in high demand. That could mean that they don't know what they are doing. That care manager held my daughter's paperwork up for over 6 months. That person wound up holding my paperwork for a very long time. I finally got a different care manager that would take over my case. I had to sign a few papers that said I'm signing my daughter's case to a new care manager. Once I did this, my daughter received her Medicaid benefits in three weeks.

You have to have a really good care manager who knows the system. You also should ask how long they've been working for the company handling the care management. In the few years we have had Medicaid, there have been five care managers. In learning more about the Medicaid system I have secured a wonderful care manager who has informed me of more benefits for my daughter. You want to make sure you have a really good care manager, someone who really is going to stay with you, and your family, and really get to know you and know your child."

Out-of-Pocket Expenses

State Medicaid programs are permitted to establish co-pays and deductibles, which may differ based on income. States cannot require out-of-pocket costs for emergency services, preventive care for children, family planning, or pregnancy-related care. However, states may apply alternative out-of-pocket expenses for beneficiaries with incomes greater than 100 percent of FPL. Out-of-pocket (OOP) expenses cannot exceed 5 percent of parental income under alternative plans.[28]

Renewals

Medicaid programs must review each beneficiary's eligibility annually. The majority of states (92 percent) are processing *automated renewals* by checking state wage databases or other sources to verify eligibility and pre-populate the renewal forms where possible.[29] The majority of states (86 percent) permit beneficiaries to create online accounts, which makes it easy to update mailing addresses and other information so that renewal forms and documentation are delivered to the correct address.[13] In addition, 41 states permit renewal applications to be completed over the phone.[29] Medicaid sends a renewal form or requests supporting documentation as necessary. After receipt of the form and/or documentation, Medicaid coverage is renewed for another 12 months. If you don't complete the renewal form or provide the documentation, your Medicaid coverage could be canceled.[13]

If you are no longer eligible for Medicaid under one enrollee category (which can happen if your income has changed), CMS recently introduced a new rule that requires states to look at alternative eligibility categories for a beneficiary so that Medicaid coverage can be maintained.[13]

Be Prepared

- Respond to Medicaid requests for information as soon as possible so that your coverage doesn't lapse.
- If your income has changed, you may no longer be eligible for Medicaid. Talk to your Medicaid or MCO representative to see if you qualify for Medicaid under other eligibility criteria.

Medicaid Waiver Programs

The federal government permits states to offer Medicaid coverage for people not in the traditional Medicaid eligibility categories, as discussed earlier in this toolkit. When a state wants to make some benefits available to specific populations, it completes a waiver application. If CMS approves the waiver program, the state is given permission to "waive" the comparability and statewide requirements.[10]

There are several different types of waiver programs, which can be created from a variety of provisions in federal legislation. There can be overlap between a state's Medicaid mandatory benefits, optional benefits, and waiver programs. For instance, a popular Medicaid benefit, **self-directed services**, may be incorporated into a state's overall Medicaid program, be part of a specific state plan for the service, or offered as a waiver program (see "Self-Directed Services" later in this toolkit).

Home and Community-Based Services (HCBS)

HCBS include services that are needed to allow the Medicaid beneficiary to live at home or in a community setting, such as a group home, instead of being hospitalized or placed in an institution. Medicaid spending on HCBS far exceeds spending on long-term care in facilities.[30] States can make HCBS to be part of their Medicaid program, offer a waiver program, or use a combination depending on the target population. Depending on which route a state chooses for HCBS (Medicaid overall program vs waiver), there can be different thresholds for eligibility and financial criteria, and different services may also be provided.[10] More than 2.5 million Medicaid beneficiaries access HCBS through a waiver program, about 1.2 million people get HCBS through a state's optional benefit of personal care services, and approximately 600,000 use home health services, a mandatory Medicaid benefit.[30]

HCBS Waiver Program Types[31]

You may hear people refer to a waiver program by its benefit offering (e.g., HCBS) or by the provision in a law that authorized the creation of the program. For instance, some HCBS waivers are sometimes called §1915(c) waivers; others may be called §1915(i).[10]

Section 1915 of the Social Security Act allows states to waive requirements for eligibility, comparability, and statewide availability for HCBS. HCBS can be offered under several provisions of Section 1915:

- 1915(c) — This provision is commonly used for HCBS waivers. The state offers payment for "medical assistance" in the home; it cannot include room and board.
- 1915 (i) — This refers to HCBS being included in a state plan.
- 1915 (j) — This is for self-directed personal assistant services. States can specify which enrollees can participate in the self-directed personal assistant services and may limit the number of beneficiaries who can participate in the program.
- 1915 (k) — Community First Choice, a state plan offering HCBS endorsed by the federal government and offered by eight states (California, Connecticut, Maryland, Montana, New York, Oregon, Texas, and Washington).[32]

In addition, some HSBC programs may be offered under a Section 1115 waiver, which is for a pilot program to test services in a state. The pilot program must assist in the state's ability to meet Medicaid program objectives.[30]

Waiver programs cannot be more expensive than if the service were to be provided in the traditional setting (e.g., a hospital). The program must protect the patient's health and welfare, ensure "adequate and reasonable standards" for the targeted group of beneficiaries, and have a patient-centered approach to care.[31] Most HCBS waiver programs require functional assessment of the beneficiary as part of eligibility for inclusion in the waiver program. Most states have local or state governmental agencies perform this assessment.[32]

States have significant flexibility in designing HCBS benefits. In general, HCBS can be segmented into the following categories:[10]

- Personal care
- Assistance with skilled health services
- Specialty care
- Adaptive services
- Family/caregiver support

Long-Term Services and Supports

Long-Term Supports and Services (LTSS) refer to non-acute care, which is healthcare delivered outside of the hospital setting. LTSS can refer to several different types of Medicaid programs, including:

- Nursing facilities for elderly enrollees (mandatory benefit)
- Home health services for senior beneficiaries and people with significant disabilities (mandatory benefit)
- Personal care services (optional benefit offered by some states)

Personal care services typically include helping Medicaid enrollees with **activities of daily living**, such as food intake, bathroom use, grooming, and dressing, among others. Since a state designs its HCBS waiver program, it can decide which benefits it will cover. In addition, it may decide to incorporate some personal care services in the waiver program and other personal care services to be used from a mandatory Medicaid benefit, such as home health services, or an optional personal care services offering that the state provides. Some states require use of employees of qualified companies, whereas others may allow the Medicaid beneficiary (or family member) to direct personal care services through a self-directed service offering.[10]

State waiver programs may also include assistance with skilled health services, such as help with medication, tube feeding, catheterization, and range of motion exercises. These typically need to be performed by a licensed nurse.[10]

Specialty services, which are targeted toward an enrollee's physical or mental impairments, may include services for functional and health needs, psychiatric rehabilitation, assistive technology, and habilitation services to enable people with intellectual or other developmental disabilities to be more independent.[10]

Adaptive services pertain to modifications to homes or vehicles to accommodate wheelchairs or other needed medical equipment.[10]

States can limit utilization of HCBS by imposing caps on hours of use or cost/spending.

About 75 percent of states have restrictions on HCBS use.

Once the limit on a particular benefit is reached, Medicaid will no longer pay for the service.

States can also require the Medicaid enrollee to contribute part of their monthly income toward HCBS costs.[32]

PRO TIP 6: WAIVER PROGRAMS IN YOUR STATE

It is tricky to find waiver programs that have been implemented in a state. *Kids' Waivers*, an online platform developed by *Complex Child Magazine*, shows Medicaid waiver programs in each state. The website also shows non-waiver programs, such as when TEFRA has been formalized as part of the state's Medicaid. On the individual state pages, Kids' Waivers also lists programs for adults.

Program descriptions and how to apply for the program are included on individual state pages. How—and where—to apply is particularly important, as some waiver programs are managed by a non-Medicaid agency or department in the state government. For instance, California has a Self-Determination Program for Individuals with Developmental Disabilities, which is managed by the state's Department of Developmental Services. The program is not managed by Medi-Cal, the name of the Medicaid program in California.

Waiver programs can limit the number of people who use a program. Kids' Waivers also shows the number of people permitted in each program, as well as the number of people on the waiting list, on individual state pages. If your state has maxed out the number of people covered under a waiver program, put your name on the waiting list. It's important to do this as soon as possible, as it can take several years before you're accepted into a waiver program. This is crucial for people with progressive rare diseases.

Waiver programs may also include family and caregiver support services, which can include training that teaches family members to use equipment. Some states offer **respite care**, in which Medicaid pays for someone to watch the Medicaid enrollee. This allows the primary caretaker(s) temporary relief in providing care. When available in waiver programs, respite care can be provided to parents of a child with complex medical needs or the spouse or adult son or daughter of an elderly Medicaid beneficiary. Many states cap the number of hours or total spending on respite care.[10]

There were more than 707,000 people on waiting lists for HCBS waiver programs in 2017. The majority of people (about 66 percent) were people with disabilities. Senior citizens comprised more than 25 percent of the waiting list. Other groups on waiting lists included medically fragile children, people with traumatic brain injury or spinal cord injuries, and those with mental illness. The average length of time on a waiting list was 30 months.[33] In 2018, the number of people on a Medicaid waiver waiting list had increased to almost 820,000, which was largely driven by additions to waiver waiting lists in Texas. The average length of time on the waiting list rose to 39 months.[32]

"Innovation" Programs

Innovation programs, which are sometimes also referred to as section 1115 waivers, may be used to introduce a pilot program or offering in a state. To offer a 1115 waiver program, states are required to demonstrate (report on) how the program improves delivery of services to an identified group of people. These waiver programs should be budget neutral.[10]

Often these programs focus on new methods for delivering care or achieving cost savings for Medicaid. For instance, 12 states use a section 1115 waiver to provide HCBS. Most of the section 1115 HCBS waiver programs are offered through a contract with a managed care organization, which puts a cap on what the state Medicaid program has to pay the MCO for HCBS.[32]

Some section 1115 waivers have recently been approved or are being reviewed by CMS that could make it more difficult to retain benefits. These include:

- **Work requirements.** Twenty-three states submitted section 1115 waiver programs with work requirements to CMS, of which 13 were approved. Four of the approved programs were blocked from taking effect by the state courts.[34] Most of these programs required Medicaid enrollees to demonstrate working or doing some sort of "community engagement" for 80 hours each month. On March 17, 2021, CMS withdrew its approval of the work requirements programs in Arkansas and New Hampshire.[35] An analysis by HHS found that Medicaid enrollment had dropped by 12 percent in Arkansas and most program participants were not aware of the work requirement one year after the program had been implemented. There were similar findings for work requirement section 1115 waiver programs in New Hampshire and Michigan.[34] Michigan's program was discontinued at the instruction of a district court.[35]
- **Healthy behavior "incentives."** A few states have received approval for section 1115 waiver programs requiring participation in a health risk assessment (HRA) and wellness program for continued Medicaid coverage. Some states used financial incentives, such as lower premiums, to encourage people to join the program. HRA completion rates have been generally low. In Iowa, 22 percent of people enrolled in the program lost their Medicaid coverage because of not completing the requirements and were unaware that they had been disenrolled from Medicaid.[34]
- **Changes to federal financing of state Medicaid programs.** Tennessee used a section 1115 waiver to request that the federal government provide an aggregate amount, instead of federal matching dollars for funds the state invests in its Medicaid program. The waiver program was approved for a 10-year period. The arrangement does not take into consideration rising per-enrollee costs. If costs rise faster than the state anticipates, there is concern the state will need to cut enrollment or benefits.[34]

Self-Directed Services

Self-directed services give Medicaid enrollees or their caretakers the ability to choose, manage, and direct payment for services. As with other Medicaid programs, the availability of the program can vary state by state. Self-directed services are most often used in conjunction with Medicaid personal care benefits or HCBS waiver programs. However, it is not an automatic offering. Of the 34 states that offer personal care services as an optional benefit, only 20 of those states permit self-direction within the program. Self-direction is available for home health services, a mandatory Medicaid benefit, in three states (California, Nebraska, and New Jersey).[32]

In some states, Medicaid gives you the ability to hire, set schedules, and fire people who provide your services. This is known as "employer authority." Some states require enrollees use an agency to oversee this function. In some states, Medicaid sets an annual budget for the enrollee and you have the ability to decide how to spend those funds. This is known as "budget authority."[36]

If your state gives you employer and budget authority, your state will likely provide you with training or other assistance to help you learn how to perform self-direction of services. The state may require you to find a financial broker experienced with Medicaid

self-direction programs. The broker typically cuts checks for services or goods that you indicate have been used as a Medicaid benefit and tracks expenditures against the budget that Medicaid has devised for you or the Medicaid enrollee. Some states allow the financial broker to perform payroll functions for your "employees."[10]

Most states permit family members and friends to perform (and get paid for providing) personal care services. However, the parents of a child Medicaid beneficiary are generally not permitted to be paid for personal care services for their child. Similarly, the adult children of an elderly Medicaid enrollee are typically not permitted to be paid for personal care services for their parent.[10]

The mechanism by which your state offers self-direction—a state plan for personal care services, HCBS waiver, or a self-directed personal assistance services program—determines what you can and cannot do. For instance, state plans for personal care services generally do not give the Medicaid enrollee budget authority, whereas HCBS waiver programs might, and self-directed personal assistance services programs require it. Cash payments to the Medicaid enrollee (or person legally responsible for the Medicaid beneficiary) are only permitted in a self-directed personal assistance services program.[10]

All states have at least one HCBS waiver program that offers self-directed services.[32] However, states can allow self-direction in one waiver program and not another. The majority of self-direction programs (57 percent) are specifically for elderly people (aged 65 years or older), followed by adults with physical disabilities (32 percent of self-directed programs). There are fewer self-direction programs for children: 28 percent of all programs are for children with intellectual or developmental disabilities, and only 9 percent are available for children with physical disabilities.[37]

RARE TIP

Kate McGlone on Self-Directed Services

"Self-direction is amazing. They asked me why self-direction and I told them I need to have control of money so I can get the right services my child needs that Medicaid doesn't pay for. Once they approve you, you need to find a financial broker in self direction and Medicaid. Medicaid provided a list of brokers who handle self-direction and you get to interview them. Think about the financial person as your staff. You're hiring them but you don't pay. The state pays the financial advisor. Self-direction allows me to have control of my daughter's Medicaid funds.

Medicaid looked at my daughter's adaptive behavior scores and other information on her. They came up with an amount that I can spend on things for her care and development. This is separate from medical costs. Medicaid will continue to pay medical costs for your children. It's almost as if your child gets a salary. You're allowed to spend it within the guidelines for use and your broker helps you with that. You can use it to pay for respite care. You can pay for camp that addresses your child's developmental needs.

You need to involve your financial advisor. The broker will give the business a form to fill out to tell how the camp program addresses your child's special needs and why it would be good for the child to attend. Once it gets approved, I tell my advisor to send a check directly to the camp.

It's important to keep receipts for purchases you make yourself so your financial broker can cut you a check to reimburse you. I can use the money to pay for sensory clothing because my child needs that. It can pay for adaptive equipment like beds and wheelchairs. You can pay for music therapy or art therapy, which Medicaid and private insurance usually don't pay for. You can pay those out-of-pocket expenses using a self-directed account, and if you pay upfront, you will be reimbursed or if you go to a self-directed approved provider, your broker will pay them directly."

Glossary

Activities of Daily Living: Every-day activities, such as eating, bathing, and going to the bathroom

Adaptive Services: Services to modify a home or a vehicle to accommodate medical equipment, such as a wheelchair

Beneficiary: The person covered by a healthcare plan

Drug Utilization Review (DUR): A board or committee that assesses pharmaceutical therapies and decides whether to include the treatments as a Medicaid benefit

Dual Eligibility: Term for when a person is eligible for two health insurance programs, such as Medicare and Medicaid, at the same time

Federal Medical Assistance Percentage (FMAP): The amount that the federal government contributes to a state's Medicaid program

Federal Poverty Level (FPL): FPL, which is updated by the US Census Bureau each year to reflect economic conditions, is used to establish a reference for income eligibility for Medicaid coverage

Home and Community-Based Services (HCBS): Services that are needed to allow the Medicaid beneficiary to live at home or in a community setting, such as a group home, instead of being hospitalized or placed in an institution

Katie Beckett Waiver: A waiver program for children with significant disabilities, offered by some states, that allows the state to disregard parental income when determining Medicaid eligibility for the child

Long-Term Services and Support: References health services and supports performed in a setting another than a hospital

Managed Care Organization (MCO): A healthcare system that strives to lower costs, manage utilization of services, and maintain quality of care

Pharmacy Benefit Manager (PBM): Pharmacy Benefit Managers manage prescription drug benefits for health insurers, Medicare part D drug plans, large employers and other payers. PBMs are companies that negotiate discounts and rebates for drugs with drug manufacturers and pharmacies.

Premiums: A monthly payment for insurance coverage

Prescription Drug List (PDL): Used by some state Medicaid programs or managed care organizations to indicate which prescription drugs are covered by the health plan

Prior Authorization: A requirement for a beneficiary to receive approval prior to receiving a treatment or service

Respite Care: A benefit in some Medicaid programs which gives the primary caretaker temporary relief in providing care to the Medicaid enrollee

Self-Directed Services: A benefit offered in some state Medicaid or waiver programs that allows the enrollee or the parents of the enrollee to direct funds for personal care services and/or other goods and services

Step Therapy: A requirement in some Medicaid drug coverage programs that an individual try and "fail" one treatment before being permitted to use a newer, more expensive therapy

Supplemental Security Income (SSI): Monthly payments sent to elderly individuals with low incomes or adults or children with a significant disability or blindness

TEFRA: The Tax Equity and Fiscal Responsibility Act of 1982, which primarily focused on closing loopholes in the federal tax code, included a provision that permitted states to provide Medicaid coverage for services provided in an enrollee's home, instead of at an institution

Waiver: A program for which federal rules and regulations related to Medicaid eligibility, service comparability, and statewide availability are "waived" for a particular group of people

Resources

Government Websites

cms.gov

Medicaid.gov

HealthCare.gov

Benefits.gov

Nonprofits and Foundations

Center for Health Care Strategies
chcs.org

Center on Budget and Policy Priorities
cbpp.org

Family Caregiver Alliance
caregiver.org

Families USA
familiesusa.org

Institute for Medicaid Innovation
medicaidinnovation.org

Kaiser Family Foundation
kff.org/about-program-on-medicaid-and-the-uninsured

Kids' Waivers
kidswaivers.org

Medicaid Coalition
familiesusa.org/our-work/medicaid-coalition

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