

Medicaid's Role for People with Disabilities

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THE KAISER COMMISSION ON
Medicaid and the Uninsured

The Kaiser Commission on Medicaid and the Uninsured provides information and analysis on health care coverage and access for the low-income population, with a special focus on Medicaid's role and coverage of the uninsured. Begun in 1991 and based in the Kaiser Family Foundation's Washington, DC office, the Commission is the largest operating program of the Foundation. The Commission's work is conducted by Foundation staff under the guidance of a bipartisan group of national leaders and experts in health care and public policy.

Medicaid's Role for People with Disabilities

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Introduction

Medicaid is the nation's major public program for providing health services and long-term care coverage to over 51 million low-income people.¹ The program is widely known for providing a safety net to low-income women and children and for financing nursing-home care for the elderly. Less recognized is Medicaid's critical role in providing health services and long-term care for adults and children with disabilities.

Medicaid, which is financed jointly by the federal and state governments, serves 8 million people with disabilities who are under age 65.² Types of disabilities include physical impairments and limitations like blindness and spinal cord injury; severe mental or emotional conditions, including mental illness; and other disabling conditions, such as cerebral palsy, cystic fibrosis, Downs Syndrome, mental retardation, muscular dystrophy, autism, spina bifida, and HIV/AIDS (Exhibit 1). Individuals with these types of disabilities often do not have access to affordable private coverage, and have chronic needs that extend beyond the services covered by the typical commercial health insurance plan.

Medicaid is unique among public and private insurance programs, in that it provides a comprehensive set of acute and long-term care benefits to meet the needs of people with disabilities. Medicaid provides access to basic medical and hospital care, prescription drugs, and long-term care services, both in the community and in institutions. Many state Medicaid programs have gone far beyond federal minimum requirements in providing coverage of services to persons with disabilities, and states have been working to increase the availability of services and supports in the community to facilitate independent living. Still, gaps remain in both the services provided and in the populations being served. In addition, eligibility for Medicaid and the type and level of services available vary considerably from state to state.

Policymakers and program administrators face tough challenges as they seek to provide high quality care for persons with disabilities. After a period of extremely low growth during the mid-1990s, Medicaid expenditures have begun to grow at a faster pace. This spending growth comes at a time when state budgets are being severely constrained by declining revenues. Because persons with disabilities have significant health needs, they are among the most costly Medicaid beneficiaries. As an increased focus is placed on limiting the growth in Medicaid spending and as the debate over the future of Medicaid intensifies, it will be critical to understand the role that Medicaid plays in the health care system for people with disabilities, including who is covered, and what services are provided. At the same time, it will be equally important to focus on how Medicaid can be improved to better address the needs of people with disabilities, so that we can continue to build on, rather than retrench from, the important gains that have been accomplished. The following is a primer on Medicaid's role as the major provider of health coverage for non-elderly persons with disabilities and on the policy challenges that lie ahead.

Interspersed throughout the primer are short profiles of people with disabilities from across the country who depend on Medicaid for health and long-term services and supports. Ranging from Patrick Quinn, a boy of eight with autism in Rhode Island who counts on Medicaid for speech therapy, occupational therapy, and home-based therapeutic services to Katie Beckett, a young woman in Iowa who relies on a ventilator to assist her breathing and whose personal story led to expanded opportunities for individuals to receive home and community-based services through Medicaid, to Greg Bechle an adult with bipolar disorder in Montana for whom Medicaid has helped remain medically stable and live in the community for nearly a decade. These personal stories help present a picture of the diverse needs of people with disabilities, the important role Medicaid plays for them, and some of the unique challenges that individuals face in getting their health and long-term support needs met.

EXHIBIT 1: TYPES OF DISABILITY

In addition to broad variations in the severity of disability, there are many ways to label different types of disability. Disabilities can be classified as either physical disabilities or mental disabilities. Also, many people with disabilities have more than one type of disability.

Mental Disability: A broad term for all disabilities that result in an impaired ability to think or learn, or that affect a person's behavior or perception. This includes mental retardation, attention deficit hyperactivity disorder, and various forms of mental illness.

Physical Disability: A broad term for all disabilities that result in impairments that affect the body's ability to function normally. This includes numerous conditions ranging from paralysis to multiple sclerosis to Parkinson's disease. It also includes conditions for which symptoms may not manifest themselves in evident ways, such as immune disorders like lupus or HIV/AIDS.

The following are an illustrative sample of different types of disability:

Bipolar Disorder: A severe mental illness characterized by repeated episodes of mania and depression.

Brain Injury: Traumatic brain injury, from wounds to the head or accidental causes, can lead to severe physical, intellectual, emotional, social, and vocational difficulties.

Cerebral palsy: A group of chronic conditions affecting body movement and muscle coordination that is caused by damage to one or more specific areas of the brain, usually occurring during fetal development; before, during, or shortly after birth; or during infancy. Cerebral palsy is characterized by an inability to fully control motor function, particularly muscle control and coordination.

Depression: An illness, involving one's body, mood, and thoughts. Major depression is one of many types of depression that is a disabling

condition that can interfere with a person's ability to work, sleep, eat, and enjoy life.

Developmental Disability: A disability that is manifested between 5 and 22 years of age and which results in substantial functional limitations in 3 or more major life activities.

Epilepsy: A chronic medical condition produced by temporary changes in the electrical function of the brain, causing seizures which affect awareness, movement, or sensation.

HIV/AIDS: A progressive immune system disorder that leaves individuals vulnerable to a wide variety of opportunistic infections that manifest themselves as the immune system is weakened.

Mental Retardation: A condition that results in significantly low intellectual functioning combined with deficits in adaptive behavior that exists from birth or childhood.

Multiple Sclerosis: A chronic, often disabling disease of the central nervous system. Symptoms may be mild such as numbness in the limbs, or severe such as paralysis or loss of vision.

Muscular Dystrophy: The common name for several progressive hereditary diseases that cause muscles to weaken and degenerate.

Parkinson's Disease: Parkinson's disease is a progressive disorder of the central nervous system characterized by a decrease in spontaneous movements, gait difficulty, postural instability, rigidity and tremor.

Schizophrenia: A condition characterized by profound disruption in cognition and emotion, affecting the most fundamental human attributes: language, thought, perception, affect, and sense of self. The array of symptoms, while wide ranging, frequently includes hallucinations and assigning unusual significance or meaning to normal events or holding fixed false personal beliefs.

Overview of Medicaid

Medicaid was established in 1965 as Title XIX of the Social Security Act. The program is voluntary for states, but provides federal matching payments of state Medicaid expenditures. The federal commitment to financing Medicaid is open-ended, and rises automatically with state Medicaid spending. Depending on the relative per-capita income of the state, the federal government pays for a minimum of 50% of total state Medicaid expenditures up to a statutory maximum of 83% of total state Medicaid expenditures. Nationally, the federal government pays for roughly 57% of total Medicaid spending.

As a condition of participating in Medicaid, states are required to cover certain “mandatory” populations. In general, Medicaid provides coverage for three basic groups of low-income Americans: children and parents, the elderly, and people with disabilities. Mandatory populations include: pregnant women and children under age 6 with family incomes under 133% of poverty (\$20,296 for a family of 3 in 2003) and older children (age 6 to 18) with family incomes under 100% of poverty (\$15,260 for a family of 3 in 2003). States must also cover parents whose income and resources are below state Aid to Families with Dependent Children (AFDC) standards as of July 16, 1996, and they must extend transitional Medicaid assistance (TMA) to low-income working families. In most cases, states are also required to cover people with disabilities and the elderly who are eligible for the Supplemental Security Income (SSI) program. In addition, states are required to assist certain low-income Medicare beneficiaries by paying their Medicare Part B premiums and, in some cases, cost-sharing.

States are permitted to extend Medicaid eligibility above mandatory requirements and continue to receive federal matching payments. Optional eligibility categories include children and parents, people with disabilities and the elderly with incomes above mandatory coverage limits; persons residing in institutions; and the medically

needy. Twenty-two percent of people with disabilities in Medicaid fall into an optional eligibility category.³ Optional eligibility has been critical to expanding access to Medicaid for people with disabilities. Seventeen states have expanded Medicaid eligibility up to the poverty level for people with disabilities, and two others have raised the income standard, although not to the poverty level.⁴ States have also taken advantage of optional eligibility categories to extend Medicaid to children and adults living at home or in the community, who would otherwise be required to reside in a nursing home or other institution to receive services.

Medically needy coverage is also an optional eligibility category that is particularly important to people with disabilities. Individuals with incomes too high to qualify through other mandatory or optional eligibility categories, yet whose medical expenses are high in relation to their income can qualify by “spending-down”. In states with these programs, individuals can qualify for Medicaid as medically needy when, after deducting medical expenses from income, a person’s remaining income is below the state’s income level for medically needy coverage (MNIL). This generally requires individuals to spend down to very low incomes. In 2001, the median MNIL was 55% of the poverty level.⁵

Medicaid also requires states to cover certain mandatory services as a condition of receiving federal matching payments. Mandatory services include: physician and hospital services, Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services for individuals under age 21, and nursing facility services for persons over age 21. States can also cover certain additional services, at state option, and receive federal matching payments. These are services that are frequently needed by people with disabilities and include: prescription drugs, physical therapy services, personal care services, prosthetics and eyeglasses, home health care services, and case management services.

The federal Medicaid statute also requires states to guarantee a range of basic protections to applicants and beneficiaries as a condition of receiving federal funding. This includes requirements that services generally must be provided statewide, so that states cannot offer services in one part of the state and deny them to individuals in another. Generally, services must also be comparable. This means that whatever decisions a state makes with regard to which optional populations to cover and which optional services to provide, it must provide them equally to all Medicaid beneficiaries when they are medically necessary (except for the medically needy). This protection serves to ensure that services are provided based on medical need and not on political considerations or other factors. The law also provides that states must provide services in an amount, duration, and scope that is reasonably necessary to achieve their intended purpose. This serves to protect beneficiaries from arbitrary limitations on services, and to ensure that covered services are provided at an adequate level to be effective. The Medicaid program also guarantees Medicaid applicants and beneficiaries due process rights, including a right to an impartial fair hearing if they have been denied Medicaid eligibility, or for beneficiaries, if they have been denied a covered service.

Medicaid programs are administered by the states, and states have broad flexibility to structure their programs. States have made very different decisions about how to operate their Medicaid

programs. Large variations can be observed across state Medicaid programs in terms of eligibility policy, covered services, payment levels for providers, and the structure of the health care delivery system. For example, many states have moved aggressively to adopt managed care programs. States such as Oregon and Tennessee serve all Medicaid beneficiaries through managed care. Wyoming, however, serves all of its beneficiaries through a traditional fee-for-service system, and does not operate any Medicaid managed care programs.

Additionally, states can gain additional flexibility and can receive exemptions from complying with the previously mentioned beneficiary protections through a waiver. The Secretary of Health and Human Services has the legal authority under various provisions of law to “waive” compliance with certain provisions of the Medicaid Act. States develop proposals that they submit for review and approval by the Secretary that would waive their compliance with the statewideness and comparability requirements, among other provisions. States have used waivers to expand coverage to new groups, to require beneficiaries to enroll in managed care programs, and to create new opportunities for receiving home and community-based services. Recently, waivers have been approved to allow states to limit Medicaid covered services to existing Medicaid beneficiary groups in order to cut spending or to expand coverage to the uninsured.

Medicaid’s Role for Adults and Children with Disabilities

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Medicaid is the nation's largest program serving the needs of low-income Americans with disabilities. Qualifying for Medicaid on the basis of a disability, however, can be complex and challenging. Medicaid's coverage is limited to those who can meet the program's definition of disability and other program rules, including limits on income and resources. As a result, not everyone who has a disability is eligible for Medicaid.

Based on past estimates, there are approximately 38 million non-elderly people with some level of disability in the United States.⁶ The National Center for Health Statistics defines a person as disabled if they have a specific physical, functional, or mental/emotional disability or limiting condition, has a lot of difficulty performing daily self-maintenance activities, uses special equipment or devices such as a wheelchair or breathing aid, and is limited in a major or other life activity due to physical, mental or emotional problems.⁷

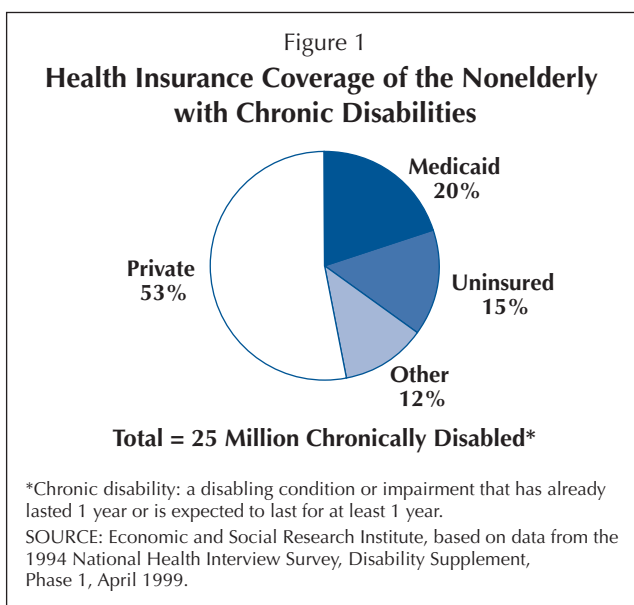
Of this broad group, 25 million non-elderly people—11% of the non-elderly population—have a specific, chronic disability.⁸ A specific and chronic disability is defined as a disabling condition or impairment that has already lasted or is expected to last for at least 1 year. For many, these disabilities are long-lasting and result in limitations in major life activities. Although the likelihood of disability increases with age, nearly 70 percent of people with severe disabilities are children or working-age adults.⁹ People with disabilities are more likely to have greater medical needs and lower incomes than others. Among working-age adults, nearly 40% of people with disabilities have family incomes less than 200% of poverty compared to 22% of the non-disabled. Medicaid covers a more severely disabled population than private insurance. Forty-six percent of adult Medicaid beneficiaries with disabilities report that they are limited in a major life activity due to a specific, chronic disability (versus just 26% of individuals with disabilities with private coverage).¹⁰ At least 458,000

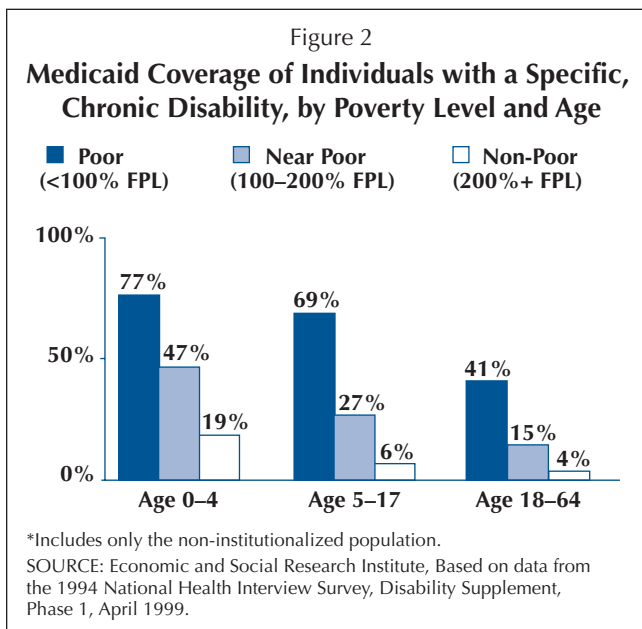
Medicaid beneficiaries under age 65 live in nursing homes, mental health facilities, or Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR).¹¹

WHO DOES MEDICAID COVER?

Many people with disabilities are not severely disabled enough or poor enough to qualify for Medicaid. Of the 25 million people under age 65 who have specific, chronic disabilities, only 20% are covered by Medicaid (Figure 1). Just over half (53%) have private insurance coverage, but these are mainly higher income individuals. Twelve percent have other sources of insurance including Medicare. Fifteen percent of those with severe disabilities do not have any insurance coverage, despite having significant health care needs.¹²

Medicaid plays a particularly important role for children with disabilities (Figure 2). Half of the 1 million children with severe disabilities age four and under receive Medicaid benefits, and 30% of the 5.3 million children ages 5 to 17 with disabilities receive benefits. Medicaid's role for those with severe disabilities is strongest for the poor—Medicaid assists seven out of 10 poor





children and 41% of poor working adults, but coverage falls off substantially as income rises.¹³ Other available sources of coverage do not fully fill in gaps in Medicaid’s coverage. Among adults and children with severe disabilities, 3.7 million have no health insurance coverage.¹⁴

WHY IS PRIVATE COVERAGE LIMITED?

Significant gaps exist in the private health insurance market for people with disabilities. Slightly more than half of all non-elderly persons with severe disabilities are covered by private health insurance. Many people with disabilities, however, do not work at jobs that provide access to employer-based group health insurance. Compounding this difficulty, individual insurance policies for persons with less-than-perfect health are usually unaffordable or unavailable. A Kaiser Family Foundation study examined the availability of individual health insurance coverage in eight insurance markets for seven hypothetical individuals with minor and serious health problems ranging from hay fever to HIV/AIDS. These “consumers” were unable to obtain coverage at the standard rate 90% of the time. Most of the

applications that were accepted included benefit restrictions and premium surcharges. The average premium for “single only” coverage was 38% more than for a policy for a person in perfect health. The individual with HIV was rejected all 60 times that he applied for coverage.¹⁵

Even individuals with disabilities who can obtain private health insurance often find that the benefits do not cover the full spectrum of their needs. Private health insurance plans are structured around providing health benefits to relatively healthy working populations, and rarely take into account the needs of people with disabilities. Core disability services including prescription drugs, mental health services, rehabilitation services, and personal care services frequently have annual or lifetime limits or are excluded altogether.

WHAT ARE THE LIMITATIONS WITH MEDICARE COVERAGE?

Individuals must meet the same standard of disability to qualify for Social Security Disability Insurance (SSDI), and thus Medicare, as for Medicaid. Nonetheless, Medicare is not available to all people with severe disabilities. In addition to meeting the definition of disability, to qualify for Medicare an individual must have a work history. Individuals earn up to four credits per year, and eligibility generally requires an individual to have at least 20 credits earned in the last 10 years before they became disabled, although younger workers can qualify with fewer credits. However, Medicare is not immediately available. After an individual meets the standard for disability, they must wait 29 months to become eligible for Medicare.

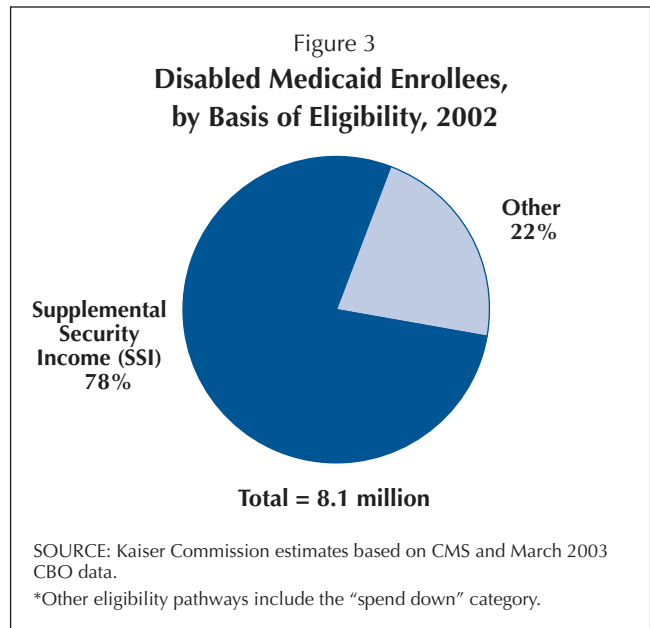
Another major limitation with Medicare is that the benefits package is inadequate for most people with disabilities. While the program works well at providing coverage for primary care and hospital services, the Medicare benefits package is notably lacking coverage for prescription drugs and long-

term care services and supports. Additionally, program restrictions that limit coverage for medical equipment and that limit access to home health services for persons who are “homebound” exacerbate gaps in Medicare coverage. Thus, even when individuals with disabilities have Medicare, many need Medicaid as a wraparound for these additional benefits.

QUALIFYING FOR MEDICAID ON THE BASIS OF DISABILITY

To become eligible for Medicaid on the basis of a disability, an individual must meet various criteria related to the severity of the disability, as well as income and resource standards, immigration status, and residency in the state where Medicaid benefits are requested.¹⁶ Individuals with disabilities who qualify for Medicaid do so primarily because they receive cash assistance under the Supplemental Security Income (SSI) program. About 78% of Medicaid beneficiaries with disabilities qualify on the basis of receiving SSI (Figure 3).¹⁷ Thus, the vast majority of Medicaid’s beneficiaries with disabilities have incomes below the poverty level.

There are additional eligibility pathways for individuals who do not receive SSI payments, but incur high medical or long-term expenses. These routes to coverage are especially important for populations using institutional services. In addition, several new state options have been established in the past several years to facilitate Medicaid coverage of the working disabled (Figure 4). Also, a parent or child with a disability may qualify for Medicaid if their family has a low-income. Adults without dependent children (who are not pregnant) generally cannot obtain Medicaid coverage.



SSI is the Primary Pathway

To meet the SSI requirements, individuals must be so severely disabled that they are unable to work, and their income and resources must be below the SSI standards. Because SSI (along with SSDI) is a program that provides cash assistance to persons unable to work, the Social Security Administration (SSA) relies on a strict definition of disability. For an adult to qualify for SSI, the SSA must determine that the individual cannot engage in any “substantial gainful activity” because of a physical or mental impairment that is expected to result in death or to continue for at least 12 months.¹⁸ Not all physical and mental impairments meet the standard of disability. For example, drug addiction and alcoholism are not qualifying conditions.¹⁹ Further, people with several disabling conditions only meet the criteria once the condition is in an advanced stage. For example, persons with HIV generally do not qualify until they have advanced HIV/AIDS.²⁰ The same is true for persons with multiple sclerosis, and other progressively disabling conditions. This is problematic since treatment is often more effective if it is received early in the course of a disease or condition.

Figure 4
Medicaid Eligibility for Persons with Disabilities, 2003

Eligibility Category	Who's Eligible?	Mandatory or Optional	Other Features
SSI	<74% of poverty* (\$552 a month) Assets: \$2,000 for an individual; \$3,000 for a couple.	Mandatory	In 39 states, SSI recipients are automatically eligible for Medicaid.
Medically Needy	50% of poverty** (\$374 a month) State sets resource standard—cannot be more restrictive than SSI.	Optional	Individuals may “spend down” to qualify by deducting medical expenses from income.
Katie Beckett Option	Would meet SSI/ Medicaid standard if institutionalized and parents’ income not attributed.	Optional	21 states use option.
Home and Community-Based Service Waivers	Individuals “at risk” of institutional care. States target certain geographical areas and specific population groups.	Optional	49 states use HCBS waivers.
Working Disabled	<450% of poverty States can set resource standard.	Optional	28 states use option.

Note: Individuals must have limited assets (below \$2,000 for an individual). The 2003 federal poverty level is \$8,980 for an individual.
 * Eleven states (209b) are permitted to set lower levels.
 **State average.

The basic SSI income standard is \$552 per month for an individual in 2003, plus any state supplementation payment (SSP).²¹ In counting income, SSI disregards the first \$65 in monthly earned income, plus one-half of the remainder. SSI also disregards the first \$20 of unearned income, with the remainder of unearned income being counted. In March 2003, there were 5.6 million non-elderly people with disabilities receiving SSI.²² Not all SSI beneficiaries automatically qualify for Medicaid. Eleven states use the 209(b) option permitting them to use their own income and asset standards and definition of disability rather than following federal SSI rules. Eligibility criteria in these states, however, cannot be more restrictive than the levels that were in place when the federal SSI program was established in 1972. If a state uses these more restrictive rules, it must also allow people with

disabilities to “spend down” into Medicaid eligibility by deducting incurred medical expenses from income. The “209(b)” states are: Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, and Virginia. Eligibility for Medicaid through the SSI pathway, whether or not the state uses the 209(b) option, is mandatory for the states.

States also have the option of extending Medicaid coverage to individuals with disabilities who are receiving SSP payments, but not SSI benefits. As of October 2001, 21 states reported providing this coverage to people with disabilities, and an additional 3 states provided this coverage only to persons who are blind.²³

The SSI rules are different for children. Policies regarding children with disabilities receiving SSI have gone through significant change over the last 13 years. In 1990, in the case of *Sullivan v. Zebley*, the U.S. Supreme Court required the SSA to properly assess children for SSI based on the applicable law at the time.²⁴ Following a period of very significant increases in the number of children becoming eligible for SSI (not solely due to the Supreme Court’s decision), Congress narrowed the SSI eligibility requirements in 1996 when it enacted welfare reform.²⁵ In 1997, following an outcry over the number of children who lost Medicaid coverage because they lost SSI eligibility, Congress restored Medicaid for children who had been receiving SSI when welfare reform was enacted. The narrower SSI eligibility requirements remain in effect, however, for children who were not receiving SSI in 1996.

A child may qualify for SSI as disabled if he or she has “a medically determinable physical or mental impairment which results in marked and severe functional limitations, and which can be expected to result in death, or which has lasted or can be expected to last for a continuous period of not less than 12 months.”²⁶ The SSA has issued a medical “listing of impairments” that serves as the basis for this determination. A child meets the SSI income

requirements if his or her countable income (taking the parents' income into account) is below the maximum monthly SSI benefit. If the child is in an institution for more than 30 days, none of the parent's income or resources is deemed available to the child in qualifying for Medicaid.²⁷

The "Katie Beckett" option (also known as the TEFRA option) makes it possible for families who are not poor, but cannot afford to keep a child with costly medical needs at home, to be able to do so.²⁸ States can offer Medicaid coverage to children who meet the SSI standard for disability and would be eligible for Medicaid if they were in an institution, but are living at home, even if the parent's income and financial resources

exceed the SSI limits. These programs are currently not available to children with disabilities who meet the SSI disability standard, but are not at-risk for institutionalization. Proposals have been made in Congress to create a state option with a buy-in program for families with children with disabilities who do not qualify for the Katie Beckett option.²⁹ Home and community-based waiver programs have also been used by states to extend services to individuals with disabilities in the community who are at-risk of institutional care. These waivers allow states to establish limits on the total number of people enrolled, as well as to target programs to selected population groups or geographical areas within a state.



Katie Beckett

Access to home-based services has allowed for a normal family life and independence

Like other kids her age, Katie Beckett, who graduated from college in 2001 wants to focus on enjoying post-college life—watching sports, going to movies, and working. At 24, she tries to keep a balance in her life, and not be overly focused on her disability. This can be challenging because Katie has a federal program named after her and, therefore, is somewhat of a public figure in the world of disability policy.

Katie was born and raised in Cedar Rapids, Iowa. When she was six months old she contracted a life-threatening case of viral encephalitis. A grand mal seizure left her in a coma for two weeks. Due to her illness, her diaphragm, left arm, and shoulder are paralyzed. Katie relies on a ventilator to assist her in breathing.

In 1981, Katie's parents' only option for receiving Medicaid assistance for their daughter was to place her in an institution. Two problems were limiting her family's options: 1) Her middle-class family had too much income to qualify for Medicaid; and 2) Home and community-based waiver options did not exist.

Eventually, Katie's story, backed by strong advocacy, led Congress to enact the "Katie Beckett option" as part of the Tax Equity and Fiscal Responsibility Act (TEFRA) in 1982. This option allows states to waive the deeming of parental income and resources for children under 19 who are living at home, but who would otherwise be eligible for institutional care. At age 31/2, Katie left the hospital, perhaps the first person to ever receive home-based care with her level of medical need.

Today, Katie is more mobile than most people who use ventilators. She says she does not use it most of the time, although she sleeps with it. Her disability continues to influence her life. Career decisions, for example, must weigh considerations such as finding reliable and comprehensive health insurance. She is leading a full life—one that may not have seemed possible just 25 years ago.

States also cover children in foster care. States are required to cover all children in foster care who receive Title IV-E payments. States have the option of covering children in foster care who do not receive Title IV-E payments. Under the Foster Care Independence Act, states have the option of extending eligibility to former foster care children between the ages of 18–21. States may cover these children if they were in foster care on their 18th birthday.³⁰

Coverage for Persons with High Medical Expenses

Some individuals with disabilities meet the SSI disability standard, but have income and assets that exceed the SSI standards. At their option, states can establish “medically needy” programs to extend coverage to these individuals (as well as other categorical eligibility groups such as the elderly, and non-disabled children and adults). Under the “medically needy” pathway, an individual who meets the SSI disability standard can become eligible for Medicaid if their income, minus their medical expenses, falls below state-established levels. The medically needy option is particularly important for individuals with disabilities who are hospitalized or in institutions, where the high cost of care can quickly drain financial resources.

Thirty-five states plus the District of Columbia operate medically needy programs.³¹ Across all medically needy programs, non-institutionalized individuals must “spend down” to a median income standard of 55% of the poverty level (States may establish different income standards for people in institutions). This means that to qualify, an individual’s income, minus medical expenses, must be less than \$4,800 a year. In Louisiana, the state with the lowest income limit, individuals must spend down to 14% of the poverty level.³² Thirteen states are not 209(b) states or do not have medically needy programs for people with disabilities.³³ In these states, individuals with Social Security, pension, and other income of more than this amount have no

opportunity to spend down, and therefore, may not qualify for Medicaid, even if the monthly cost of their care exceeds their income.

For individuals residing in institutions, some relief is offered by the state option to use a “special income rule” for persons in need of institutional services. States have the option of extending eligibility up to 300% of the SSI benefit (\$1,656 per month in 2003) for individuals in nursing facilities and other institutions, including ICFs/MR. If their countable income is under the state-established limit, institutionalized individuals who also meet the SSI resource test can qualify for Medicaid. Thirty-eight states have elected to cover this group.³⁴

Facilitating Coverage for Working People with Disabilities

Many individuals with disabilities are able and want to work, but have great difficulty obtaining affordable private health insurance coverage because their employer does not offer coverage, they cannot afford coverage, or they are denied coverage based on their health condition. For many individuals with disabilities, Medicaid coverage is the only way to secure the personal attendant services, prescription drugs, and other medical services they need to remain independent. As discussed earlier, under SSI policy, an individual must have a severe “medically determinable physical or mental impairment” and be unable to engage in “substantial gainful activity,” defined by the SSA as earnings of no more than \$800 per month in 2003.³⁵ Individuals with disabilities who earn more are at risk for losing Medicaid without necessarily being able to obtain or afford private coverage. In the face of substantial health care needs, this policy serves as a disincentive to work.

To address this problem, several policy options have been created to facilitate greater access to Medicaid coverage for individuals with

disabilities with incomes greater than SSI standards. Twenty-one states allow higher-income working individuals with disabilities to obtain Medicaid coverage as long as they meet the SSI disability standard.³⁶ The Balanced Budget Act of 1997 (BBA) gave states the option to set their own income and resource standards, up to 250% of the poverty level.³⁷ States also can use less restrictive methodologies to count income and assets to raise these thresholds. In 2001, Minnesota had one of the most generous standards, disregarding all income up to 250% of the poverty level for persons with up to \$20,000 in countable resources. States that use this option can charge premiums and impose cost-sharing on a sliding scale based on income. In 1999, Congress raised the income ceiling to 450% of the poverty level with passage of the Ticket to Work and Work Incentives Improvement Act. The Ticket to Work legislation also prohibits states from charging premiums that exceed 7.5% of income for persons with income of between 250% and 450% of the poverty level.³⁸

The 1999 law also allows states to extend Medicaid coverage to working individuals with disabilities whose health conditions improve. The individual still would need to have a “severe medically determinable impairment”—a diagnosis by a physician that the person still has a disability.³⁹ While these laws create opportunities for states to eliminate barriers to employment for people with disabilities, many states have not taken advantage of them.

WHAT SERVICES DOES MEDICAID PROVIDE FOR PEOPLE WITH DISABILITIES?

Medicaid beneficiaries with disabilities need access to a broad range of medical and chronic care services. About half of adult beneficiaries with disabilities have a physical impairment, one-fourth have some form of limitation in performing activities of daily living, and 40% have severe mental symptoms or disorders.⁴⁰ Persons with

disabilities insured by Medicaid are substantially more impaired than are other individuals with disabilities. Almost 60% of Medicaid beneficiaries with a chronic disability are limited in a major life activity because of their disability compared to 37% of privately insured persons with disabilities.⁴¹

Medicaid cover standard medical benefits, such as physician and hospital care, diagnostic services and testing, and prescription drugs. In addition, Medicaid commonly covers rehabilitation services, personal care, case management, nursing home care for adults, therapeutic services, transportation, medical equipment, and home health services. Over half (57%) of Medicaid expenditures on persons with disabilities are for acute care services, while the remaining 43% is for long-term care services (Figure 5).⁴² Long-term care involves providing a range of supportive services that assist individuals with performing

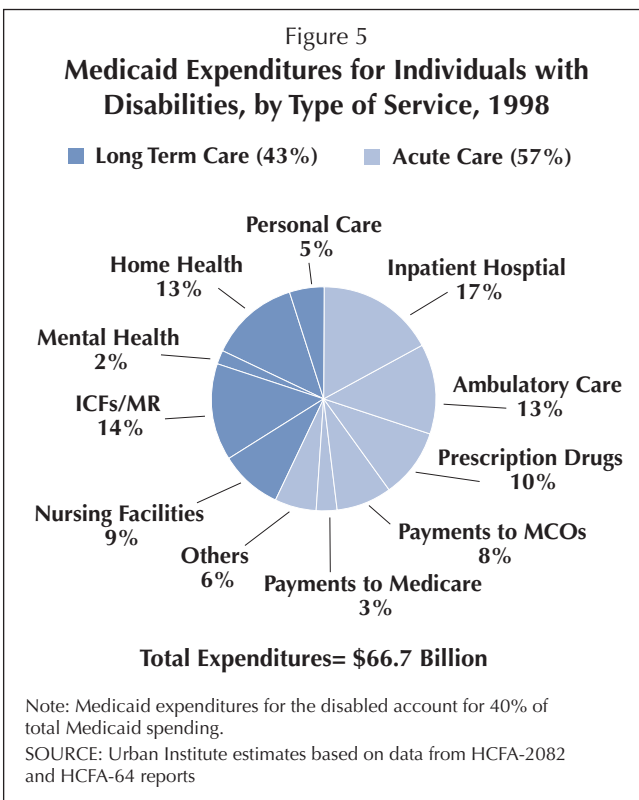


Figure 6
Medicaid Benefits, Acute Care

“Mandatory”

- Physician’s services
- Laboratory and x-ray services
- Inpatient hospital services
- Outpatient hospital services
- Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services for individuals under 21
- Family planning and supplies
- Federally-qualified health center (FQHC) services
- Rural health clinic services
- Nurse midwife services
- Certified nurse practitioner services

“Optional”

- Prescription drugs
- Medical care or remedial care furnished by licensed practitioners under state law
- Diagnostic, screening, preventive, and rehab services
- Clinic services
- Dental services, dentures
- Physical therapy and related services
- Prosthetic devices, eyeglasses
- TB-related services
- Primary care case management services
- Other specialist medical or remedial care

activities of daily living and instrumental activities of daily living. These range from providing assistance with eating, dressing, and toileting to assisting with managing a home, preparing food, and using the telephone. Individuals with disabilities are high users of inpatient care, physician care, and prescription drugs. The bulk of long-term care spending is concentrated on institutional care and reflects the high cost of providing these services. A relatively small share of Medicaid spending is devoted to community-based care. As more people with disabilities receive home and community-based services, however, the proportion of Medicaid spending on home health and personal care services is likely to rise.

Federal Medicaid law requires that the states provide certain services to everyone covered by the program. Such mandatory services, particularly important for people with disabilities, include

physician and hospital services, Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services for children, institutional services for adults, and home health care services for individuals entitled to nursing facility care (Figure 6). Medicaid law also defines optional services that states can elect to provide. The list of optional services includes a broad range of disability-related services, such as prescription drugs, case management, rehabilitation services, personal care services, home and community-based waiver services, and ICF/MR services (Figure 7). Many of the disability-related services covered by Medicaid, including case management, rehabilitation, and personal care services, are not typically covered in private health insurance policies.

Although prescription drugs are an optional benefit, all Medicaid programs cover them because

Figure 7
Medicaid Long-Term Care Benefits

“Mandatory”

“Optional”

Institutional Services

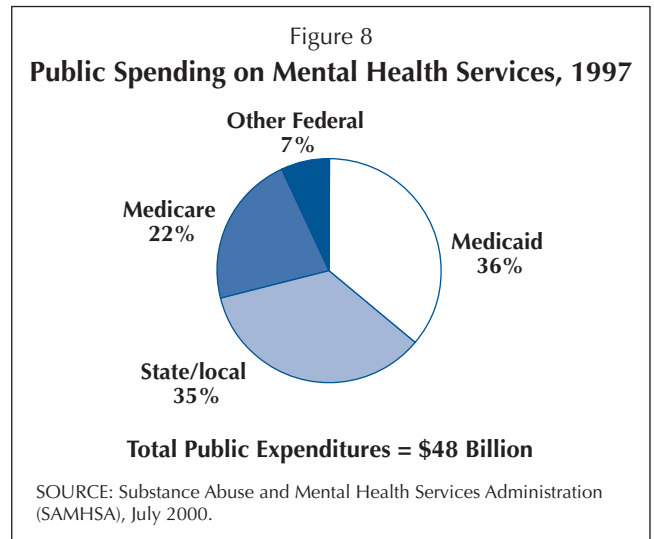
- | | |
|---------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> • Nursing facility (NF) services for individuals 21 or over | <ul style="list-style-type: none"> • ICF/MR services • Inpatient/nursing facility services for individuals 65 and over in an institution for mental diseases (IMD) • Inpatient psychiatric hospital services for individuals under age 21 • Home health care services |
|---------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

Home & Community-Based Services

- | | |
|-----------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> • Home health care services (for individuals entitled to nursing facility care) | <ul style="list-style-type: none"> • Case management services • Respiratory care services for ventilator-dependent individuals • Personal care services • Private duty nursing services • Hospice services • Services furnished under a PACE program • Home- and community-based services |
|-----------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

of their clinical significance. For people with disabilities, access to prescription drugs is essential to the management of acute and chronic physical and mental illnesses. For some conditions, prescription drugs have become the primary tool for managing disability. The development of behavioral health medications that are efficacious and tolerable to patients is transforming the treatment of many types of mental illness. Advances in the treatment of epilepsy are producing a standard of care where the growing expectation is that most people can become seizure-free with no side effects. Further, the development of medications to slow the progression and treat conditions ranging from HIV/AIDS to Parkinson's disease are both extending life and reducing morbidity—and in some cases, reducing health care expenditures by eliminating the need for costly inpatient hospital services.

Every state covers home and community-based services for at least some individuals at risk of institutional care. Most states provide these services through home and community-based services (HCBS) waivers, also known as 1915(c) waivers. Waivers allow states to be exempted from certain Medicaid requirements in order to provide targeted services to specific populations or to experiment with new ways to deliver health care services. HCBS waivers provide a wide range of non-institutional long-term care services, and states have considerable flexibility to determine which services and populations to cover under HCBS waivers. Some of these services, such as case management or personal care, could be covered as optional services. Others, including homemaker/home health aide services, adult day care services, habilitation services, and respite care can only be covered through a waiver. States are not permitted, however, to cover room and board under home and community-based services waivers.



Medicaid also has become the principal public payer of mental health services (Figure 8).⁴³ States have taken steps to maximize Medicaid financing of mental health services by providing care in settings such as psychiatric units of general hospitals, where federal matching dollars are available, rather than placing them in psychiatric hospitals (Institutions for Mental Disease, IMDs) where services are not covered by Medicaid. States also have increasingly used Medicaid to pay for community-based mental health services, which can be covered under a number of different benefit categories.

For the medically needy, Medicaid allows states to provide a more limited package of benefits. Disability-related services that would be mandatory for other groups are not necessarily covered benefits for medically needy individuals in many states. In most states, however, states offer the same benefits package to the medically needy as they offer to other Medicaid beneficiaries.

GREG BECHLE

Medicaid has helped an adult with bipolar disorder to remain medically stable for roughly 9 years

Greg Bechle of Missoula, Montana knows how serious mental illness can be and how challenging it can be to qualify for Medicaid. In 1985, Greg was a teacher with a master's degree in education who experienced a series of brief episodes of psychosis (wherein he temporarily lost contact with reality). As a result of these episodes, Greg lost his job. Reflecting on that time in his life, he says that he was not able to function very well. Untreated, Greg's mental illness worsened.

In 1991, he says that he became "totally insane". At one point, he walked from Missoula to Stevensville, Montana—30 miles away—and threw a rock into a neon sign of the local newspaper for which he had been working. He was arrested for felony criminal mischief, and incarcerated for a month. During this time, he was denied access to appropriate medical care. He was diagnosed with paranoid schizophrenia and given haloperidol (Haldol). Haloperidol is a psychotropic drug that has been around for many years that many people find difficult to tolerate. Greg says that taking haloperidol was horrible. During this period, Greg was uninsured, so he relied on family members to purchase medication for him. He applied for

Medicaid, but he was turned down because he did not meet the standard for disability.

In 1993, Greg was hospitalized again. He was given lithium, which helped, but was inadequate. He said that he was okay in the hospital, but out in the real world, he would have problems. Later that same year, after a serious episode, he wound up in the Montana State Hospital where he was diagnosed as having bipolar disorder. Apparently, the earlier diagnosis of paranoid schizophrenia was incorrect. In 1994, Greg applied again for Medicaid. This time, with a more extensive record of mental illness, he was determined to be eligible.

Fast forwarding to 2003, Greg has been relatively medically stable for 9 years and has received Medicaid for 8. He currently takes a combination of 4 drugs to manage his bipolar disorder. He takes lithium, as well as risperidone (Risperdal), trihexiphenidyl (Artane) and valproic acid (Depakote). While more expensive than the older drugs like haloperidol, his current medications are both more effective and cause fewer side effects. Greg says that Medicaid has been a lifesaver for him. "I was a risk to myself and to others—and I also kept tying up law enforcement." Greg also makes the case for Medicaid covering his medications—even the newer and expensive ones. He estimates that the total monthly cost for his medications is roughly \$350. He says that this is cheaper than even one day in the hospital.

Overall, most state Medicaid programs provide a range of benefits that are more appropriate to the needs of people with disabilities than many other public and private health insurance programs. With private insurance and Medicare, many individuals with disabilities may face barriers to care in the form of high cost-sharing or limited benefits package. Furthermore, Medicaid does not have pre-existing condition exclusions or impose a waiting period for coverage.

Medicaid Fills in Gaps for Medicare Beneficiaries

Over 7 million of Medicaid's 51 million beneficiaries are "dual enrollees," low-income elderly and persons with disabilities who are enrolled in both Medicaid and Medicare.⁴⁴ While Medicare covers basic health services including physician and hospital care, dual enrollees rely on Medicaid to pay Medicare premiums and cost-sharing and to cover critical benefits, such as

long-term care and prescription drugs, that Medicare does not cover. Medicare cost-sharing requirements can be an enormous barrier to care for low-income Medicare beneficiaries. For example, the Medicare Part A deductible, currently \$840 per benefit year, is more than three times as high as the deductible typically imposed by large employer plans.⁴⁵

Medicare beneficiaries with disabilities with incomes slightly higher than the income standard for mandatory Medicaid eligibility can still receive some Medicaid benefits. In states that have raised the income standard to the poverty

level, individuals qualify for full Medicaid coverage. In all states, mandatory coverage options exist for individuals above the mandatory income standard, but these programs do not provide the full package of Medicaid benefits. Further, the level of benefits declines as income rises (Figure 9). A person with an income of less than 100% of the poverty level can qualify for the Qualified Medicare Beneficiary (QMB) Program. The QMB program pays the cost of Medicare Part B premiums (\$58.70 per month in 2003), which provides access to physician services, and covers

Figure 9
Medicaid Eligibility for Medicare Beneficiaries, 2003

Pathway	Income Eligibility	Asset Limit	Medicaid Benefits
Mandatory			
SSI Cash Assistance*	<74% of poverty (SSI income eligibility)	\$2,000 individual or \$3,000 couple	"Wrap-around" Medicaid benefits including long-term care and prescription drugs. Medicaid pays Medicare Part B premium and cost-sharing.
Qualified Medicare Beneficiary (QMB)	<100% of poverty	\$4,000 individual or \$6,000 couple	No Medicaid benefits. Medicaid pays Medicare Part B premium and cost-sharing.
Specified Low-Income Beneficiary (SLMB)	100–120% of poverty	\$4,000 individual or \$6,000 couple	No Medicaid benefits. Medicaid pays Medicare Part B premium.
Optional			
Medically Needy	Individuals who spend their income down to a specified level	\$2,000 individual or \$3,000 couple	"Wrap-around" Medicaid benefits may be more limited than for SSI Cash Assistance.
Special Income Rule for Nursing Home Residents	Individuals in institutions with income <300% SSI level	\$2,000 individual or \$3,000 couple	Medicaid pays for "wrap-around" benefits including Medicare Part B premium and cost-sharing.
Home and Community-Based Services Waivers	Individuals who would be eligible if resided in an institution		"Wrap-around" Medicaid benefits including long-term care and prescription drugs.

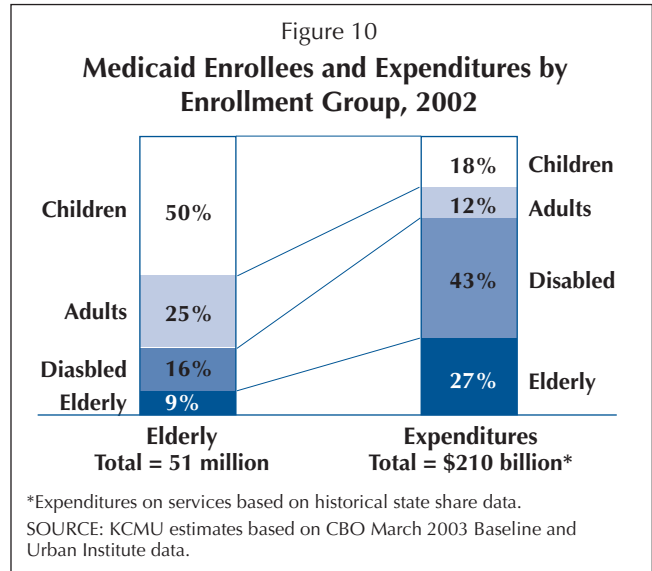
Note: Under the Qualifying Individuals (QI) program, Medicaid pays the Medicare Part B premiums for individuals with income between 120 and 135% of poverty. The QI program is funded under a block grant that has been extended to September 30, 2003.* States that elect the so-called "(209b)" option can set lower levels. Also, states have the authority to expand eligibility up to 100% of poverty.

Medicare cost-sharing expenses. Persons with incomes of between 100% and 120% of the poverty level can qualify for the Specified Low-Income Medicare Beneficiary (SLMB) Program. SLMB covers the Medicare Part B premium only. States also receive federal block grant funding to provide Part B premium assistance to persons with incomes of up to 135% of the poverty level on a first-come, first-serve basis.⁴⁶

HOW MUCH DOES MEDICAID SPEND ON BENEFICIARIES WITH DISABILITIES?

On average, Medicaid beneficiaries with disabilities require more extensive health care services than most other beneficiaries. While beneficiaries with disabilities represented only 16% of Medicaid enrollees in 2002, they accounted for 43% of expenditures (Figure 10).⁴⁷ Persons with disabilities are more likely to have chronic medical conditions that lead to more

physician visits, higher rates of hospitalization, greater use of prescription drugs, and increased need for long-term care services, compared to



Marta Lucia Piñales

For a kidney transplant recipient, Medicaid has provided a critical supplement to Medicare

Marta Lucia Piñales* is a 32-year-old New Yorker. Medicaid, which supplements her Medicare coverage, has played a key role in her life. Until she was 11, Marta did not have any major health problems. She started having health problems that her doctors diagnosed as lupus, a condition not often found in children. Lupus is a chronic autoimmune disease where the immune system, for unknown reasons, becomes hyperactive and attacks normal tissue, including vital organs.

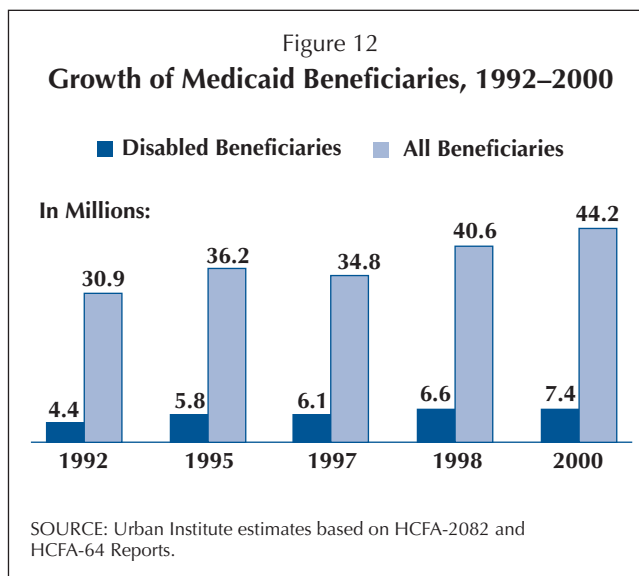
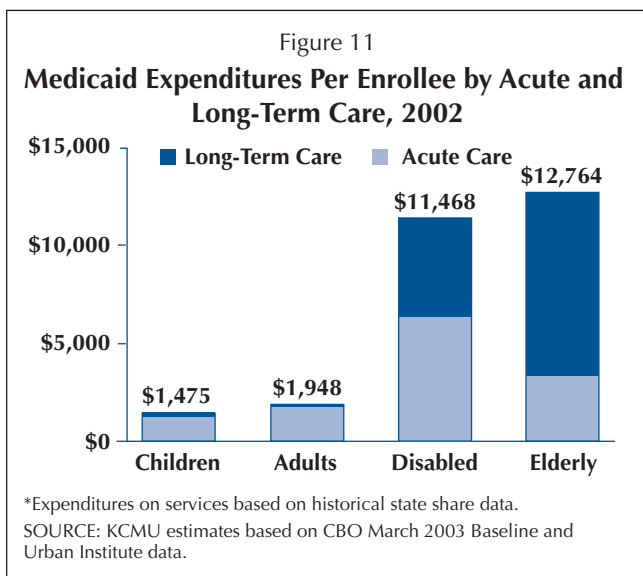
By age 17, Marta started showing her first signs of kidney failure. A year later, she was placed on dialysis. At this point, a social worker helped her and her family apply for both Medicare and Medicaid. Medicare paid for most of her dialysis costs and Medicaid picked up the difference. Although she initially received hemodialysis, she switched to peritoneal dialysis

because it meant that instead of going to a clinic to receive dialysis, Marta was able to dialyze in her home. The dialysis, which took 10 hours daily, was done at night while she slept, which gave her the independence needed to enroll in college.

When she was 22, Marta needed her first kidney transplant, which she received from her father. Medicare covered the cost of the transplant surgery and her drug costs for 36 months, with Medicaid paying supplemental costs during this time. After 36 months, however, the Medicare benefits ran out and she depended on Medicaid to cover her drug costs for the anti-rejection medications. She will need to take these medications for the rest of her life. She takes more than 10 medications two times a day both to prevent rejection of the transplanted kidney and to control the symptoms of lupus. Marta estimates that her monthly drug costs are at least \$1,200.

Marta has had two subsequent kidney transplants. Despite these challenges, Marta is clearly focused on her future. Because she has been able to count on both Medicaid and Medicare, Marta was able to finish her bachelor's degree in Communications and Journalism from Queen's College three years ago.

*Not her real name.

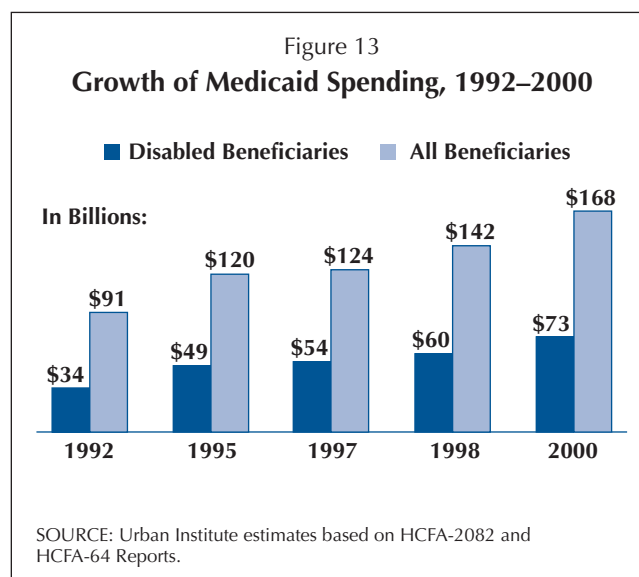


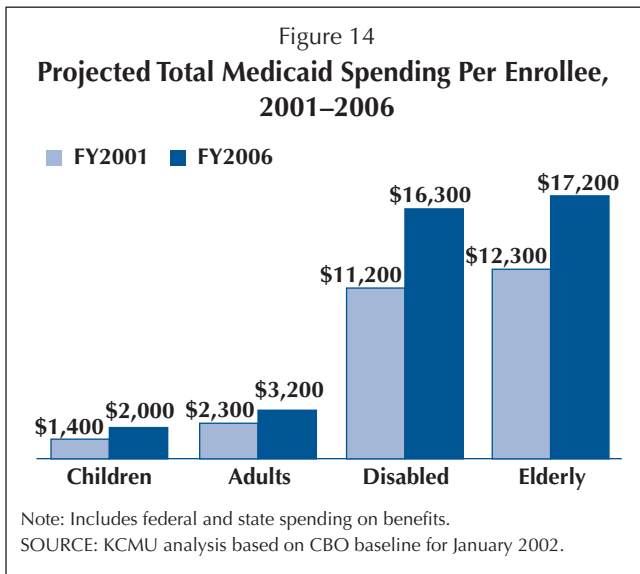
low-income families. ICFs/MR are heavily utilized by non-elderly people with disabilities, as are home and community-based services. The average per-person cost of caring for persons with disabilities in 2002 was \$11,500 (Figure 11).⁴⁸ This compares to \$1,500 for non-disabled children and \$2,000 for non-disabled adults. Only elderly Medicaid beneficiaries, at an average cost of \$12,800, were more costly.

National data mask substantial variation in benefit spending trends from state to state. For example, in 2002, only 6 states spent over 50% of long-term care spending on home and community-based care. By contrast, 12 states spent less than 2% of long-term care expenses on home and community-based care services.⁴⁹

During the 1990s, the number of Medicaid beneficiaries with disabilities grew more rapidly than the growth in total enrollment (Figure 12). From 1995 to 1998, enrollment of people with disabilities grew while the overall Medicaid population declined. As a result, Medicaid spending on people with disabilities grew faster than spending on the overall Medicaid population

(Figure 13). Between 1997 and 1998, spending growth for people with disabilities was 9.7% compared to 6.2% for all Medicaid beneficiaries.⁵⁰ These trends are expected to continue over the next few years. According to projections, per-enrollee spending on persons with disabilities will surpass \$15,000 in fiscal year 2005—more than five times the projected spending on non-disabled adult Medicaid beneficiaries (Figure 14).⁵¹





About two-thirds of projected increases in disability-related costs over the next few years are related to serving the current caseload, while the rest is associated with serving new beneficiaries.⁵² Health care costs for current beneficiaries are expected to rise because of increased costs for health care and because beneficiaries are likely to use more services.

Federal Medicaid costs increased 13.2% from FY 2001–FY 2002 and are increasing in FY 2003 by 7% over FY 2002, according to the Congressional Budget Office (CBO).⁵³ From FY 2002 through 2013, CBO projects that federal Medicaid costs will increase at an average annual rate of 8%.⁵⁴ That’s nearly double the 4.9% annual increase from 1995 to 1999.

Medicaid’s Accomplishments and Challenges in Meeting the Needs of People with Disabilities

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The Medicaid program plays a pivotal role for low-income people with disabilities. Medicaid is truly a lifeline that promotes access to a comprehensive set of acute and long-term care services that is absent in the private sector and Medicare. Access to these services can make the difference between living as independently as possible, and deterioration in health, economic, and social circumstances. Medicaid's accomplishments for people with disabilities stand out in a number of areas, including making prescription drug therapies available, especially to persons with mental illness and HIV/AIDS; covering personal care services not paid for by private payers or Medicare; paying for case-management services to help organize and coordinate services; and Medicaid financing of institutional services has helped to raise the quality of care provided in institutions generally.

Increased pressures on state budgets due to plummeting revenues and rising health care costs are making it difficult to continue to make progress and build on Medicaid's achievements for people with disabilities. States have called on the federal government for more help in paying for Medicaid and more discretion over how Medicaid funds are used. In the face of this fiscal crisis, the Bush Administration has put forward a proposal that would allow states to convert much of their Medicaid programs to a block grant. This proposal would fundamentally restructure how Medicaid has always operated as a federal and state partnership, with a strong federal commitment to financing and fostering state innovations to improve the program. As discussions at the federal and state level unfold, it is essential to understand how alternative policy choices would affect Medicaid's ability to meet the needs of people with disabilities.

BUILDING ON MEDICAID TO ADDRESS GAPS IN COVERAGE FOR PEOPLE WITH DISABILITIES

Estimates indicate that nearly four million adults and children with severe disabilities are uninsured.⁵⁵ Uninsured individuals are much more likely to face barriers to health care services and experience worse health outcomes compared to those with insurance. Finding ways to extend and improve coverage to people with disabilities is critical.

Recent policy efforts have been directed at expanding Medicaid coverage to people with disabilities in two areas: removing financial disincentives to work and addressing gaps in coverage for those who have progressive disorders, but who are not yet severely disabled. While the SSI program provides a floor of minimum coverage across the country, limiting Medicaid coverage for people with disabilities poor enough to qualify for cash assistance has proven to be too restrictive in view of the gaps in the private insurance market. In addition, some individuals forgo work opportunities in order to maintain eligibility. In some cases, parents have not taken jobs that pay higher wages because the higher income would force their children to lose Medicaid coverage. Some persons with disabilities whose conditions have somewhat improved have turned down jobs because the income could threaten their Medicaid eligibility.⁵⁶

States have substantial flexibility to broaden eligibility rules to cover more individuals with disabilities. The new working disabled options created under the BBA and Ticket to Work Act provide states with substantial flexibility to cover people with disabilities who are working and may have income and resources that exceed the SSI level. Some states have used the working disabled options, as well as Section 1115 waiver authority to expand Medicaid coverage to people with disabilities. States have also used 1115 waivers to expand coverage to new populations, including specific groups of people with

disabilities. Maine, Massachusetts, and the District of Columbia, for example, have been granted demonstration waivers by the Centers for Medicare and Medicaid Services (CMS) to extend Medicaid benefits to non-disabled persons with HIV/AIDS.⁵⁷ In Maine, for example, participants must be HIV-positive and have an income of less than 300% of the poverty level.⁵⁸ Despite the availability of this flexibility to extend coverage, a relatively small number of states have taken advantage of these opportunities.

ASSURING AN ADEQUATE BENEFITS PACKAGE

Individuals with disabilities often have substantial medical and long-term care needs. In addition, specific needs vary considerably across population groups. A benefits package needs to provide the full spectrum of services to effectively meet these needs and foster independence. The Medicaid benefits package is broad and flexible, and thus enables states to cover services to meet the range of needs experienced by people with disabilities. There are some areas, however, where benefits particularly important for persons with disabilities have not always been made available by states.

EPSDT Services for Children with Disabilities

The Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit requires that all children covered under Medicaid receive all medically necessary services. EPSDT includes periodic screening (including a comprehensive health and development history, physical exam, appropriate immunizations, laboratory tests including lead blood level assessments, and health education), vision services, including eyeglasses, dental services, hearing services, including hearing aids, and other necessary care and treatment to correct or ameliorate defects and physical and mental illness and conditions. EPSDT is an important benefit, both because of its breadth and because if a child is discovered to need a service as a result of an EPSDT screening,

the state must pay for the services whether or not it is ordinarily covered by that state. For example, if a child is determined to need extensive physical therapy services, and those services are not covered for adult Medicaid beneficiaries, the child is still entitled to coverage. Early intervention can often minimize or prevent life-long disability. Unfortunately, states have not always ensured that children receive EPSDT services and some states have faced lawsuits charging them with not providing all necessary services.⁵⁹

Access to Prescription Drugs

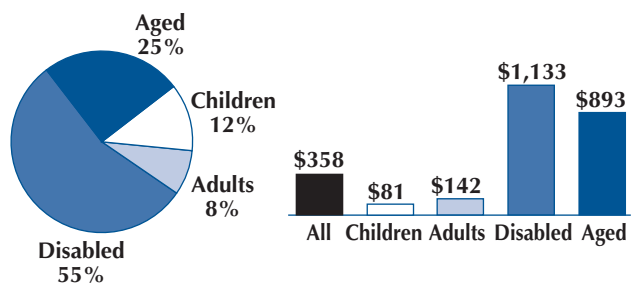
Prescription drug coverage is an essential component in the management of acute and chronic physical and mental conditions. Prescription drug coverage is optional under Medicaid, but all states provide this benefit. Adequate access to prescription drugs is critical for people with disabilities who may rely on these medications to control conditions so that they can work, live in the community, and avoid unnecessary hospitalizations. With continuing therapeutic advances, the role of drugs in caring for Medicaid beneficiaries with disabilities is expected to continue to increase. In the case of HIV/AIDS, for example, prescription drugs have dramatically reduced morbidity and mortality. While drug regimens can be expensive, costing in the range of \$10,000–\$12,000 per beneficiary a year for antiretroviral therapy alone, they can potentially reduce overall costs by reducing expensive hospital stays.⁶⁰ The role of pharmaceuticals in treating people with disabilities is only expected to increase, with advances in genetics and molecular biology leading to the development of new therapeutics for a range of conditions.

Because the costs of drugs are rising faster than many other expenses and due to fiscal pressures, states are taking a number of measures to reduce drug use among Medicaid beneficiaries, including those with disabilities. More than half (55%) of all Medicaid spending on prescription drugs is for

Figure 15

Medicaid Prescription Drug Spending, 1998

Expenditures by Eligibility Group Expenditures per Enrollee



*8.2% of total Medicaid spending on services. Includes both fee-for-service expenditures and estimated drug spending by managed care organizations
SOURCE: Urban Institute Estimates, 2000.

people with disabilities (Figure 15). A number of states have imposed new prior authorization requirements, while others have limited the number of prescriptions that beneficiaries can receive in any given month. In some states, only one medication in a broad class is covered; for instance, a state may cover only one anti-psychotic medication, though different drugs in the spectrum of anti-psychotic drugs may work better on a particular patient. Some options (utilization review, generic substitution) have the potential to curb spending growth while also improving or maintaining quality of care. Other strategies, such as increased cost-sharing or the imposition of caps, may in fact place an undue burden on beneficiaries with disabilities who may require multiple prescriptions or access to newer drugs. The growing role of prescription drugs and increasing costs challenge states to design appropriate limits, while still providing necessary access to prescription drugs.

Access to Rehabilitation and Therapy Services and Medical Equipment

The importance of several critical disability services that Medicaid covers may be underestimated because these are services not often used by people who do not have disabilities. Various types of therapy services, such as physical

therapy, occupational therapy, or speech and language therapy are critical to supporting individuals in minimizing the burden of disability and maximizing independence. For example, access to speech and language therapy services may mean that individuals with certain neurological conditions are able to communicate with others. Physical therapy services help people with conditions such as cerebral palsy to maintain control over their muscles—a defining symptom of their type of disability. Occupational therapy services help people with disabilities learn skills for performing activities of every day life and address psychological, social and environmental factors that impede independent functioning. Because persons with disabilities may be more susceptible to certain types of injuries, rehabilitation services are also critical in helping individuals to recover quickly and to regain and maximize their ability to function in ways that may have been already impaired, due to disability.

In addition to therapy services, people with disabilities also depend heavily on equipment, supplies, and technological innovations that produce new tools for maximizing independence. Durable medical equipment (DME) and supplies is a category of services that covers a broad range of equipment and physical supports from wheelchairs and walkers to oxygen. Although DME and medical supplies are critical to people with disabilities, they are optional services. Access to these services, in some states, may be constrained by state policies, or by other factors such as low provider reimbursement rates, which create barriers to accessing certain services.⁶¹ Two facets of Medicaid policy sometimes may place constraints on people with disabilities accessing the DME services: 1) Covered DME is generally restricted to equipment necessary for use in the home. For example, this may mean that a person can get a wheelchair for use in getting around their house, but in some circumstances they cannot obtain a multiple terrain wheelchair that would enable them to get



Patrick Quinn

Through Medicaid, a child with autism receives critical home and community-based services

Joanne Quinn says that she was relieved when her son Patrick, now age 8, was diagnosed with autism. At least the family knew what was going on—and could explain his behavior. “Before his diagnosis, the whole household was stressed and ready to explode.” Autism prevents individuals from properly understanding what they see, hear, and otherwise sense. This results in severe problems with social relationships, communication, and behavior.

Patrick was diagnosed with autism at age 4, which is unusually late. This reflects, in part, the fact that Patrick functions at a relatively high level for a child with autism. After his diagnosis, Patrick started to receive Medicaid through a Katie Beckett home and community-based services program. Two years later, Patrick started to receive additional services through a Medicaid waiver. The most important services he

receives are speech therapy, occupational therapy, and home-based therapeutic services (HBTS) for 20 hours a week. In the case of a child like Patrick, occupational therapy consists of teaching him a broad range of life skills, such as how to dress, how to make his bed, and how to respond to other children who may act strangely around him.

From the Quinns’ perspective, the Katie Beckett program is one of the many good things about Medicaid. They feel fortunate to live in a state (Rhode Island) that has enacted the optional program. They also really like the EPSDT requirement because it allows Patrick to receive needed services that the state may not otherwise cover.

Despite these protections, the Quinns believe there are gaps in Medicaid’s coverage. Patrick was on a waiting list for more than two years to get the home-based speech and occupational therapy services he needed that were not available through Rhode Island’s regular Medicaid program. During this time, the Quinns spent roughly \$25,000 of their own money each year on a private home-based worker and other services not covered by Medicaid. It is a challenge to work in the Medicaid system, Joanne says, because of the sheer time it takes to fight for necessary services.

out of their house, and travel independently; and 2) Covered DME generally does not allow access to motorized equipment, unless an individual is unable to use a manual wheelchair.⁶² This has the effect of prohibiting a person who uses a wheelchair from getting access to a motorized wheelchair until they develop a secondary disability (such as chronic shoulder problems) from using a standard wheelchair.

ASSURING THAT MANAGED CARE WORKS FOR PEOPLE WITH DISABILITIES

About one in four non-elderly people with disabilities in Medicaid were enrolled in managed care in 1998.⁶³ Although their needs are often more complicated and extensive than low-income families, few states have developed specialized managed care programs for persons with

disabilities. Systems to monitor quality in managed care environments are still evolving and most states have not implemented efforts specific for persons with disabilities. In addition, assuring adequate payments to managed care plans for people with disabilities continues to be a challenge for states.⁶⁴

One area of particular importance is the management of mental health benefits. Many state Medicaid managed care programs have “carved-out” behavioral health care benefits. This means that they have contracted with managed care organizations that specialize in managing mental health services under a separate contract from the managed care organization that provides primary medical care and other health care services. These behavioral health carve out programs have been controversial. States have



Christopher Gipson

Medicaid provides essential health insurance coverage for a teenager with sickle cell disease and Moyamoya disease

Christopher Gipson, age 16, of Gambrills, Maryland has sickle cell disease and other related health concerns. Christopher was diagnosed with sickle cell disease at birth. At age 8, he had a serious stroke that has caused on-going neurological disorders, including Moyamoya Disease, a potentially life-threatening condition that causes the main artery to the brain to narrow or close. These conditions have impaired his development. While he is currently in the tenth grade, his reading and math skills are at the level of a second grader and his verbal comprehension skills are roughly that of a sixth grader. His stroke has also had other long-term effects. He now experiences seizures, and he is aphasic, meaning that he is impaired in his ability to use or comprehend words.

It can be challenging for Christopher to receive high quality care because he has two conditions that require highly specialized care. Christopher is enrolled in a Medicaid managed care program (MCO) with a limited network of providers, including specialists. Despite the fact that Christopher receives Medicaid, his mother, Cynthia, purchases a parent/child individual health insurance policy for roughly \$5,200 a year, which serves as his primary insurance, with Medicaid providing supplemental coverage. When asked why Christopher needs Medicaid if he has private

coverage, Cynthia explained that his private coverage first requires an \$800/person deductible and then only covers 75% of his remaining medical expenses. His need for regular transfusions, each of which cost roughly \$10,000, is a financial burden. Last year, the cost of his care not covered by private insurance was \$12,000, roughly half of their total family income.

Since May 2002, Christopher has been enrolled in a special Maryland Medicaid waiver called Rare and Expensive Case Management (REM). This program provides a case manager to help a small group of Medicaid beneficiaries with rare and expensive conditions to coordinate their care and enables them to see providers with fewer restrictions. Christopher's mother says that since Christopher enrolled in the REM program, she has been much happier with his Medicaid MCO because she does not need to get referrals to see specialist providers.

Paying for the private coverage is a huge expense for the Gipson family. Christopher's mom says she makes this financial sacrifice so that Christopher can continue to see his existing providers, which have the appropriate knowledge and experience to care for him. She also pointed out that Christopher needs the ability to access out-of-network providers when he visits his father who lives in another state.

Like most parents, Cynthia will do what she needs to help her son prepare for a happy and productive life. She says that his health problems have not stopped him from leading an active life. He is active in his church, sings in the school chorus, participates in the Special Olympics, and he is a testimonial speaker for his local Red Cross.

often adopted this approach because mental health services comprise a significant portion of spending for people with disabilities and mental health benefits are perceived to be a complex benefit that may require more intensive management. Private behavioral managed care organizations have also promised cost savings in the range of 20%, due to decreased inpatient hospitalizations. These arrangements have

frequently led to consumer complaints that they are unable to receive the mental health services they need, and it has also created challenges in coordinating care between multiple care providers.⁶⁴

Included in the BBA were provisions that required the development of a Report to Congress on special protections needed to ensure that the

health care needs of individuals with special health care needs and chronic conditions enrolled in Medicaid managed care organizations are adequately met.⁶⁵ The Bush Administration withdrew regulations issued by the Clinton Administration and published new final regulations in June 2002. All state Medicaid managed care programs must comply with these regulations as of June 2003. Although consumer advocates criticized the changes in the regulations, in particular the elimination of several specific requirements related to persons with special health care needs, the regulations establish significant new consumer protections with regard to access to information, network adequacy, and the adoption of a “prudent layperson” standard for access to emergency care.

The future direction of managed care enrollment for individuals with disabilities in Medicaid is not clear. States do not appear to be obtaining the same savings for Medicaid managed care as they did in the mid 1990s. Many plans have left Medicaid because of concerns over rates, administrative burdens, and difficulty in negotiating with hospitals and physicians because of provider consolidations. In many states, capitation rates have been increased to maintain the participation of the plans that remain. Since managed care is unlikely to produce additional savings for states, there is likely to be less financial incentive to enroll additional people with disabilities into managed care. Additionally, several states are also moving to less restrictive models for managing care, such as adopting primary care case management (PCCM) programs instead of full-risk capitated programs.

INCREASING THE AVAILABILITY OF HOME AND COMMUNITY-BASED SERVICES

States have expanded the availability of home and community-based services (HCBS) by applying for federal 1915(c) waivers. These waivers provide states with the flexibility to cover a wide range of services to facilitate community living, while also

permitting states to limit the numbers of persons eligible and the regions in which these services are available. States also must demonstrate to CMS that coverage of services under HCBS waivers would be budget neutral to the federal government. This means that the state estimates that the average per capita Medicaid expenditure for individuals covered by the waiver will not exceed what the state would have spent without the waiver.

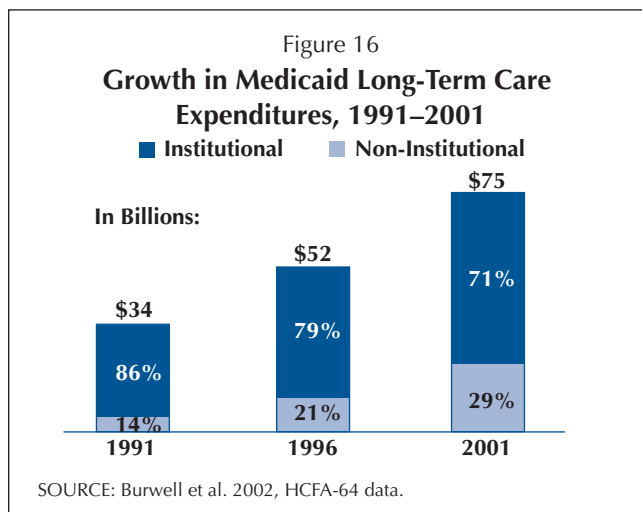
In addition to personal care and case-management services, HCBS waivers provide states with substantial flexibility to cover services such as homemaker/health aide services, adult day health services, habilitation services, and respite care that would not ordinarily be covered by Medicaid. For individuals with chronic mental illness, home and community-based services include day treatment or partial hospitalization services, psychosocial rehabilitations services, and clinic services. Because states can target a particular subset of the Medicaid population or a particular area of the state, it limits the availability of these services. As a result, some persons with disabilities end up in institutions because community-based services are not available. Though community-based services can be more cost-effective than institution-based services on a per-person basis, states worry that overall costs will rise if benefits replace much of the unpaid care that family members now provide in the home.⁶⁶

In 2001, there were 229 waivers in 49 states serving over 800,000 people.⁶⁷ Waiting lists for waiver programs are long. More than half of the states have waiting lists for home and community-based services.⁶⁸ While spending on home and community-based services waivers is growing, it only accounted for 29% of total Medicaid spending on long-term care in 2001 (Figure 16).⁶⁹

While advocates and policy makers may agree that home and community-based services are preferable in many circumstances, Medicaid has a bias in favor of institutional care. Greater use of

home and community-based services waivers is limited to some extent by the policy that they must be targeted to individuals at risk of

institutionalization and the requirement that they be budget neutral to Medicaid. Thus, offsetting savings to other programs, such as Medicare, by reducing hospitalization rates, are not considered by the Department of Health and Human Services in determining whether home and community-based waiver programs are budget neutral.



The states also are still formulating responses to the 1999 U.S. Supreme Court decision that could expand home and community-based services for persons with disabilities. In *Olmstead v. L.C.*, the court ruled that unjustified institutional isolation of persons with disabilities is a form of discrimination and a violation of the Americans with Disabilities Act.⁷⁰ The decision does not require states to provide community-based services in all circumstances, though. The Department of Health



Morris Turner

Medicaid coverage enabled a person with cerebral palsy to move away to college

To look at Morris Turner, you probably would not guess that one of his favorite things to do is to go white water canoeing. Morris, 39, a resident of Silver Spring, Maryland, has cerebral palsy—so for many people, looking at him is to underestimate him.

Morris developed cerebral palsy as a result of complications during his birth. His disability results in him struggling to get his words out, and he has limited control over his muscles. He is, however, able to work the controls of his motorized wheelchair, and this gives him some freedom to go out and do things.

In some ways, Morris is a case study in both the successes and failures of how our nation supports people with disabilities. Because of Medicaid, which paid for in-home health care workers to come

in and care for him every morning and state vocational rehabilitation programs that paid for a personal assistant, Morris was able to attend Frostburg State College in western Maryland and live in a dormitory. While he enjoyed college-life, he said that sometimes it was such a struggle simply to coordinate his services that he felt like there was not much time left for learning. Nonetheless, he made it, earning a B.S. in economics.

Following college, Morris had several jobs, including working for a member of Congress. Since losing that job in 1994 (due to the change of power after the election), Morris has been unable to find another job—a situation that is not uncommon for people with disabilities. Morris really would like to work. His inability to find a job that can accommodate his support needs results in part from Medicaid services that are no longer available to him. As a child, the EPSDT benefit ensured that personal care and attendant care services were provided for him. As an adult, these benefits are optional benefits that are not provided to him by Medicaid in his state. While Medicaid clearly provides critical services, his situation demonstrates that more services are sometimes needed to fully integrate people with disabilities in the workplace and in the community.

and Human Services has issued guidance to state Medicaid directors urging them to develop “comprehensive effectively working plans for placing qualified persons with disabilities in the most integrated setting appropriate”.⁷¹ Currently, 40 states and the District of Columbia have created task forces or commissions to assess their current long-term care systems and to develop plans.⁷² About half the states have issued plans or intended to in 2002.⁷³ However, it is unclear what will come out of the plans. Some of the recommendations have been to strengthen consumer choice and information, improve the quality of care in nursing homes, use Medicaid waivers to expand and create new opportunities for people with disabilities to live in the community, and address transportation barriers.⁷⁴

In the fall of 2002, the Bush Administration announced the Independence Plus waiver initiative. This program is intended to give states new opportunities within Medicaid to allow individuals with disabilities and persons who are elderly to have greater involvement, control, and choice in identifying, accessing and managing the services they obtain to meet their personal assistance needs. People with disabilities and the elderly have advocated strongly for greater control in hiring and firing of personal attendant workers. Through this initiative, individuals could also hire family members to provide personal assistance services. The Independence Plus waiver program is an expansion and modification of previously approved “Cash and Counseling” waivers that were first established in 1996. While beneficiaries in the cash and counseling waivers were highly satisfied with the self-direction provided through the waiver program, the success of the Independence Plus program at meeting the needs of people with disabilities will depend on ensuring that the individual budget is adequate for the range of services to be managed by the individual.

ASSURING THE QUALITY OF INSTITUTIONAL CARE

Nursing home quality of care is a concern at the state and national level. As the population ages and the need for nursing home care grows, the nation’s nursing homes are an increasing subject of concern. Congress passed major nursing facility regulation in 1987 (OBRA 87). Although the quality of nursing home care has improved since the regulations were implemented in the early 1990’s, quality concerns persist today. According to a General Accounting Office report released in March 2002, 30% of nursing homes have been cited for deficiencies involving harm to residents or placing them at high risk of death or serious injury.⁷⁵

As part of the larger examination of nursing home quality, Congress and others have begun to focus on the adequacy of nursing home staffing levels and the relationship between staffing and quality. To qualify for Medicaid funding, nursing homes must meet federal staffing requirements. These standards require nursing homes to have a registered nurse on duty eight consecutive hours per day and a licensed nurse to be on duty 24 hours a day. There are no federal minimums for non-licensed assistant staff. In addition to the federal minimums, most states have set their own staffing standards.⁷⁶

Many studies show a positive relationship between higher nurse staffing levels and better care outcomes. CMS and an expert panel sponsored by the Hartford Institute for Geriatric Nursing put forth recommendations on the level of nursing staff necessary to guarantee resident safety. Both sets of recommendations present higher staffing levels than federal and, in many cases, state staffing requirements. Recent survey findings show that actual median staffing levels in nursing homes are higher than state minimum standards and much higher than federal requirements, however, they are still lower than both the CMS and Hartford Panel recommendations. As state and federal

polymakers continue to grapple with how to improve the quality of care in nursing homes, they will need to ensure that staffing levels are adequate for quality of care.⁷⁷

RESTRUCTURING MEDICAID THROUGH SECTION 1115 WAIVERS

Broader use of waivers to restructure Medicaid coverage and benefits is likely to be at the forefront of future policy discussions. Waivers can be useful tools to demonstrate new ways to provide coverage and deliver services to vulnerable populations. The 1915(c) home and community-based services waivers have been important vehicles that states have used to provide services to people with disabilities in non-institutional settings. States have also used Section 1115 waiver authority to conduct statewide demonstrations to expand coverage to populations beyond current federal options. The waivers being considered now, however, could move beyond the expansions in coverage and revisions in benefits and service delivery that have been approved in the past and bring about fundamental changes for Medicaid beneficiaries. Under the Health Insurance Flexibility and Accountability (HIFA) Initiative, states have used these waivers to impose greater cost sharing and reduce benefits for current beneficiaries in order to provide for nominal eligibility expansions to the uninsured (although new coverage groups have not been guaranteed the full Medicaid benefits package, and in one state, they were provided only a primary care benefit without coverage for hospital or other services).

For people with disabilities, the new waiver policy raises several concerns. HIFA offers states broad flexibility with respect to benefit and cost-sharing rules for optional groups, and permits states to cap enrollment. These optional groups include the medically needy, the working disabled, and many individuals who qualify for home and community-based waiver services, including children in Katie Beckett waiver programs.

Under the HIFA guidance, states can substitute a State Children's Health Insurance Program (SCHIP) benefit package for Medicaid benefits for optional beneficiaries. The SCHIP minimum requirements are generally based on health plans available to federal or state employees and would not include many of the disability-related services needed by people with disabilities. The HIFA guidance also strongly encourages states to seek waivers to use Medicaid funds to subsidize the purchase of private coverage. This means that benefits might be limited to whatever benefit package was available under the employer plan.

Finally, the waivers are intended to be budget neutral. The waivers move state Medicaid programs away from open-ended federal financing to a capped financing arrangement. Under HIFA policy, the ceilings or caps on the amount of federal matching funds that will be provided will be adjusted based on the number of people covered and projected medical inflation, but they will not be adjusted if costs exceed projections due to higher than anticipated inflation, changes in utilization, technology, or the need to increase providers rates to maintain or improve access to care or quality of care. The elderly and individuals with disabilities are high users of care and account for more than 80% of Medicaid spending for optional groups. Eligibility and services for these populations could be jeopardized by the budget neutrality constraints.

MOUNTING BUDGET PRESSURE AT THE STATE LEVEL

Revenue shortfalls, combined with increasing Medicaid costs, are creating significant budget stresses in many states. Spending on services, especially prescription drugs and nursing home care, are factors in Medicaid spending growth. Federal law gives states broad discretion in adjusting Medicaid expenditures. In deciding whether to reduce state Medicaid spending, however, states must consider not only the impact on beneficiaries, but also the loss of federal

matching funds to their health care economies. The upward trend in Medicaid spending tracks, to a large degree with the trends in private sector health spending, with health care inflation explaining much of the growth in spending. Cost increases in the private sector put pressure on Medicaid programs to keep pace as a major purchaser of care. To maintain access to care for beneficiaries, state Medicaid programs are being pushed to raise payment rates for providers and health plans, and to pay for the escalating cost of prescription drugs.

The tightening budget situation, coupled with the increased growth in Medicaid spending, has prompted states to explore strategies for controlling cost growth. Forty-nine states and the District of Columbia implemented Medicaid cuts in FY 2003 and 32 states that enacted Medicaid reductions earlier in the year, revisited the Medicaid budget and made cuts a second time in the year. Some of the cost containment measures states had implemented included: 37 states reduced or froze provider payments to hospitals and nursing homes; 45 states implemented prescription drug cost controls; 27 states report that they cut or restricted Medicaid eligibility; 25 states reduced benefits, and 17 states increased co-payments.

The range of services provided by Medicaid are often critical to keeping people with disabilities alive or maintaining their quality of life. Since Medicaid is generally the only place that individuals with disabilities can receive these essential services, even seemingly modest cutbacks, or reductions in provider payments that lead to lost access to specialist providers, can have an enormous impact on access to appropriate health care. Nonetheless, in addition to previously enacted reductions, a number of states are also considering cutting back or eliminating their “medically needy” programs, which provides a last chance for accessing Medicaid. Seventeen states also report they will reduce long-term care spending, and this may

lead to states putting on hold planned expansions of home and community-based services.⁷⁸

In response to the state fiscal pressures, legislation was enacted in May 2003 as part of the tax cut bill giving \$20 billion in fiscal relief to the states, including \$10 billion to temporarily increase federal matching payments for Medicaid. These funds will lower the states’ share of Medicaid expenditures in 2003 and 2004. These additional federal funds could be used by the states to reverse or forestall previously planned cutbacks to their Medicaid programs.

Against this backdrop, the Bush Administration has put forward a proposal that would offer states greater discretion to make changes in their Medicaid programs in return for a cap on federal spending. States would receive an up front boost in federal funding if they take the block grant approach, but this would be offset by a reduction in federal funding in later years. States that opt for the block grant would give up the guarantee of open-ended federal matching funds on state covered services, a central feature of Medicaid since its inception.

As Medicaid enrollment and spending has grown, federal matching payments have been available to states to help shoulder these costs and make program improvements a reality. The federal commitment has enabled states to be responsive to the needs of people with disabilities and experiment with a variety of new approaches to providing Medicaid services. It has also fostered program innovation, such as supporting state interest in developing HCBS waivers and state efforts to expand access to Medicaid coverage. Capping federal funds would make it more difficult for states to expand access to Medicaid coverage for people with disabilities and could result in retrenchment as the disability population competes with other populations for limited funds.

Under the proposal, states would have flexibility

over coverage of “optional” beneficiaries, including many who qualify as working disabled or receive home and community-based services, and “optional” services, including prescription drugs, prosthetic devices, and personal care services. Two-thirds of Medicaid spending on the disabled is for optional populations and services. The loss of federal protections could result in discrimination against Medicaid beneficiaries in ways that are currently prohibited. For example, states could place arbitrary limits on covered services, so that Medicaid programs could

provide less of a service than a health professional believes is necessary. States would be permitted to provide a broader package of covered services to some beneficiaries than others, without regard to their medical needs. For SSI-eligible individuals with disabilities who depend on prescription drugs, personal care, and a broad range of optional services, and for any optional eligibility group, this plan could erode the entitlement to services.

Conclusion

As policymakers consider proposed changes to Medicaid, it will be important to keep Medicaid's central role in providing health care and long-term supports to the most severely disabled low-income people in the United States at the forefront of these discussions. This makes it necessary to evaluate the impact of the proposed changes on people with disabilities. It will also be important to consider the failure of the private market-and Medicare-to provide broad access to benefits packages that provide the range of services and supports needed by people with disabilities as reform options are considered. Indeed, the heavy burden on Medicaid for providing comprehensive disability and long-term care services and supports stems from the absence of such coverage elsewhere, and the attractiveness of leveraging federal dollars by directing state health care spending through Medicaid.

It is hoped that the real people profiled in these pages and the issues discussed will help inform an appreciation of the role of the Medicaid program. For nearly 40 years, Medicaid has evolved as medical advances and a greater appreciation for the role of people with disabilities in society has changed the expectations on the program. Further, the flexibility provided by the open-ended financing structure and other program features has allowed states, through numerous state options, demonstration programs, and HCBS waivers to innovate, and test new approaches to providing health and long-term supports and services to people with disabilities. Ensuring that people with disabilities receive the health care and supportive services they need to stay healthy and participate fully in public life is an important policy priority.



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