

medicaid and the uninsured

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Aging Out of EPSDT: Issues for Young Adults with Disabilities

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Introduction

Medicaid is a nationwide health coverage program for low-income Americans, funded jointly by the federal government and the states. It provides critical health services and long-term care for 52 million people, including 8 million people under age 65 with severe disabilities, of whom over a million are children and youth under age 21. More than one of every five children with disabilities has Medicaid coverage, and 7 out of 10 poor children with disabilities are covered by Medicaid.

Children enrolled in Medicaid may have a variety of disabilities, including mental disorders, such as mental retardation and mental illness and physical disabilities, such as blindness, spinal cord injuries, and cerebral palsy. A majority of children receiving Supplemental Security Income (SSI), one of the primary pathways to Medicaid coverage for disabled children, has a primary diagnosis of mental disorder, including mental retardation, developmental disability and mental illness.¹ This measure does not capture children with multiple disabilities, and, therefore, provides only an incomplete picture of children with disabilities in Medicaid.

Medicaid is a partnership between the federal government and the states. The federal government establishes broad eligibility and benefit guidelines, but grants the states considerable flexibility to set their own income eligibility levels and define covered services. As a result, there is great variation across the states in terms of who is covered under Medicaid and what services they receive. However, where children are concerned, the federal government imposes stricter standards, requiring higher income eligibility thresholds than states are permitted to set for adults, and, until passage of the Deficit Reduction Act (DRA) of 2005, mandating a comprehensive set of health and long-term care services. The basis for the federal government's uniform and higher Medicaid standards is the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit, specified in the Medicaid statute.

For children with disabilities, having access to a comprehensive range of services is especially important. Many of these children may be medically fragile and have complex needs for specialized and supportive services, in addition to the more mainstream services that all children need. The EPSDT mandate is instrumental in ensuring that children with disabilities in particular, have access to the services they need. However, as these children progress from adolescence to adulthood, they are no longer eligible for EPSDT. Many lose Medicaid coverage

altogether once they reach adulthood, due to more stringent Medicaid eligibility rules for adults. Those who retain Medicaid eligibility have access only to the benefits offered to adults, which are nearly always much more limited.

The DRA, signed into law on February 8, 2006, made significant changes to the Medicaid program. It changed the current benefit rules for non-disabled children and parents to permit states to enroll these populations into “benchmark” or “benchmark-equivalent” plans that typically provide more limited coverage. The DRA also allows states to provide different benefits to different populations and in different geographic regions in the state. Despite this increased flexibility, states must still provide children with EPSDT benefits either directly through the benchmark plans or as a wrap-around service. Certain populations, including children and adults who are eligible for Medicaid based on a disability, are exempt from these benefit changes. However, many children who have significant disabilities but who do not qualify for Medicaid on that basis will be subject to the new benefit changes.

The DRA also made important changes to Medicaid long-term care services by allowing states in the future to provide home and community-based services as a state plan option. This provision would eliminate the need for states to obtain a waiver to provide these services.

This issue brief discusses the challenges and implications for young people with disabilities of losing the EPSDT benefit when they become adults. This brief focuses on those children with severe disabilities who, if they maintain Medicaid coverage as adults, will do so on the basis of their disability. Therefore, the discussion of the Medicaid benefit package for adults is limited to the existing federal rules, which will continue to apply to adults with disabilities.

What is EPSDT and Why Is It Important for Children with Disabilities?

The Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit is, in effect, the package of Medicaid benefits for children. Under EPSDT requirements, states must provide comprehensive health and developmental assessments, and vision, dental and hearing services to children and youth. In addition to screening services, EPSDT also covers the diagnostic and treatment services necessary to ameliorate acute and chronic physical and mental health conditions.

The EPSDT benefit was originally enacted in 1967, in response to high rejection rates for new military draftees that were attributed to untreated childhood illnesses. In 1989, the EPSDT benefit was amended to include stronger provisions concerning the required types and periodicity of screening services. The goal of the periodic screening and comprehensive health assessments is to identify health conditions in children early, when intervention services can be most effective. These interventions can be tailored to a child’s developmental stage to offer the maximum potential for improvement.

The 1989 amendments added another key provision – the requirement that states provide children all medically necessary services permitted under the Medicaid statute, whether or not the services are otherwise covered under the state’s Medicaid plan, and without regard to any restrictions the state may impose on the services for adults. The effect of this provision is that EPSDT ensures more comprehensive benefits for children than are generally offered to adults in the same program, or than they would likely be able to obtain through a typical private insurance

plan. For example, the EPSDT benefit encompasses services such as physical, occupational, and speech therapy, respiratory care, personal care services, mental health services, and durable medical equipment, as needed.

In addition to the broad scope of services to which it provides access, EPSDT also applies a broad definition of medical necessity for children, whereas states can develop their own medical necessity definitions for others. Specifically, the EPSDT provision states that services must be provided “to correct or ameliorate defects and physical and mental illnesses and conditions.” This conception of medical necessity, rather than requiring services only if they improve or eliminate a condition, requires services needed to stabilize conditions or maintain function. For children with disabilities and chronic illnesses, for whom medical services are not likely to correct or cure their conditions, these kinds of services can improve the chances of leading fuller and more independent lives.

How is Medicaid for Adults Different from EPSDT for Children?

When children reach adulthood (anywhere from age 18 to 21 depending on the state in which they live), they are no longer eligible for EPSDT. Instead, those who retain Medicaid eligibility as adults, primarily based on their disability and qualification for SSI, are eligible for the set of services that their state covers for adult beneficiaries. States have fairly broad discretion to design their Medicaid benefit packages for adults, a fact with important implications, especially for individuals with disabilities, whose needs are more varied and extensive.

Federal law establishes three classes of services that states either must or may cover for adults: mandatory services, optional services, and home and community-based services (HCBS) provided through a waiver. Medicaid law requires coverage of 12 “mandatory” services, including EPSDT, inpatient and outpatient hospital care, physician services, nursing home care, and home health services. The statute also specifies a list of “optional” services, each of which a state may elect to cover (Table 1). If a state chooses to cover an optional service, it must provide it statewide and to all beneficiaries. Finally, states can provide home and community-based services (HCBS) through waivers. Home and community-based services include such services as personal care services, private duty nursing services, and case management services, that enable people with disabilities to live at home or in group settings in the community. Federal statute allows states to cover additional services through a waiver, such as adult day care and respite care, that are not permitted under the state plan. However, under HCBS waivers, states have the authority to limit access to services in a variety of ways. They can cap enrollment in their waiver programs, or they can limit access to services geographically, or based on individuals’ age and/or disability.

As distinct from the rules that apply to children under EPSDT, states are authorized, where adults are concerned, to set limits on the amount, duration, and scope of the services they cover, whether the services are mandatory, optional, or provided under a waiver. Further, states can impose much narrower definitions of medical necessity for adults than EPSDT prescribes for children. For example, a state might not consider a treatment, drug, therapy, or device medically necessary if it does not cure an adult’s disability, even if it assists in maintaining the individual’s health or independence.

Table 1

Medicaid Mandatory and Optional Statutory Benefits

ACUTE CARE	
<u>Mandatory Items and Services</u>	<u>Optional Items and Services</u>
Physicians' services	Prescription drugs
Laboratory and x-ray services	Medical care or remedial care furnished by licensed practitioners under state law
Inpatient hospital services	Diagnostic, screening, preventive, and rehabilitative services
Outpatient hospital services	Clinic services
EPSDT	Primary care case management services
Family planning services and supplies	Dental services, dentures
Federally-qualified health center (FQHC) Services	Physical therapy and related services
Rural health clinic (RHC) services	Prosthetic devices, eyeglasses
Nurse midwife services	TB-related services
Certified nurse practitioner services	Other specified medical and remedial care
LONG-TERM CARE	
<u>Mandatory Items and Services</u>	<u>Optional Items and Services</u>
	<u>Institutional Services</u>
Nursing facility services for individuals 21 and older	Inpatient hospital and nursing facility services for individuals 65 or over in an institution for mental disease (IMD)
	Inpatient hospital and nursing facility services for individuals 65 or over in an institution for mental disease (IMD)
	Inpatient psychiatric hospital services for individuals under age 21
	<u>Home & Community-Based Services</u>
Home health care services for individuals entitled to nursing facility care	Home health care services
	Case management services
	Respiratory care services for ventilator-dependent individuals
	Personal care services
	Private duty nursing services
	Hospice care
	Services furnished under a PACE program
	Home and Community-based (HCBS) services (under waiver, subject to budget neutrality requirements)

What Does Losing EPSDT Mean for Young Adults with Disabilities?

Potential Loss of Medicaid Eligibility

The first hurdle young adults encounter is that of establishing their continued eligibility for Medicaid. The only pathway to Medicaid eligibility for young adults without children is receipt of SSI benefits combined with low income (74 percent of the Federal Poverty Level or \$7,252 in most states). Many children with disabilities lose Medicaid coverage when they become adults because they cannot qualify for SSI as adults. It is estimated that 74 percent of children on Medicaid with potentially disabling medical conditions such as severe asthma, diabetes, HIV, cancer, and cystic fibrosis meet Medicaid eligibility criteria based on their age and family income but do not meet the disability standards required for receipt of SSI.² Research indicates that about 400,000 of these young people are at risk of losing their Medicaid coverage once they reach the age limit in their state for eligibility as a child because they will not qualify for SSI.³ Even those young people who qualify for SSI as children are not guaranteed continued coverage as adults. The Social Security Administration (SSA) applies more stringent disability criteria for adults than for children. SSA redetermines eligibility for SSI for all 18-year-olds receiving the benefit to determine whether they meet the stricter eligibility criteria applied to adults. The majority of those who receive SSI benefits as minors remain eligible as adults. But an estimated 25 to 30 percent of these young adults with disabilities are found not to be eligible.⁴ Once individuals become ineligible for SSI, most lose Medicaid coverage as well. A recent study found that over half of young people who lost SSI eligibility at redetermination became uninsured.⁵

More Limited Access to Services

While EPSDT mandates comprehensive coverage of medical and long-term care services for children, the terms of Medicaid coverage change markedly once children reach adulthood, providing much more limited access to services. For young adults with disabilities, these limits have particularly important implications.

The more restrictive benefit package typically offered to adults is consequential. Many of the services and supports that young adults with disabilities may continue to need to maintain function and remain in the community, such as personal care and respiratory care services, are considered optional for Medicaid adults. While all 50 states cover at least some optional services, few, if any, cover all optional services for adults. For example, in 2005, 29 states provided no coverage for private-duty nursing, and 22 states did not cover personal care services as a statewide service.⁶

Limits on the amount, duration, and scope of covered benefits for adults further reduce access to services for young adults with disabilities. For example, some states cover private-duty nursing, but only for individuals with ventilator dependency. While all states elect to cover prescription drugs, four states limit prescriptions to between three and six per month.⁷ Similarly, states that cover physical, occupational, and speech therapy for adults often limit the number of sessions an

individual may receive in a year. For young adults with disabilities, whose needs are ongoing and may be maintenance-oriented, such limits may be counter-productive.

States' medical necessity criteria for adults, which generally require rehabilitation or correction of a condition, represent a fundamental shift from the much broader EPSDT definition. Thus, services that a young adult with disabilities may need simply to maintain function, such as physical or occupational therapy, though previously covered under EPSDT, may now be denied.

Over the last 20 years, states have made extensive use of HCBS waivers to expand Medicaid access to community-based supports. Indeed, from 1999 to 2002, the number of Medicaid beneficiaries receiving care through HCBS waivers increased 32 percent.⁸ However, whereas these waivers enable states to supplement the services available to children under EPSDT, in many states, they are the main mechanism for providing community-based services to adults with disabilities. Consequently, adults who do not qualify for a waiver or who are placed on a waiting list for such care are unlikely to receive the Medicaid services needed to meet their ongoing needs. In short, enrollment caps and other state restrictions associated with HCBS waivers limit the access of adult Medicaid beneficiaries with disabilities to services that are critical to maintaining function and maximizing independence.

Decline in Health

Limited access to needed services can have serious consequences for young adults with disabilities. A recent study of health access and use among adult SSI recipients in New York City revealed that nearly half these individuals visited the emergency department within the previous year, and over a quarter had multiple visits.⁹ Over one-third of these same individuals also reported unmet need for health and mental health services, including doctor care, prescription drugs, and special medical equipment.¹⁰ Multiple visits to the emergency department suggest that a chronic disabling condition is not being well-managed.

The failure to adequately manage a chronic condition can, over time, lead to a deterioration in health status. Already vulnerable and at-risk for complications arising from very serious conditions, young disabled adults can face serious problems as a result of even minor disruptions in care. These disruptions occur when services covered for children are not covered for adults.

For adults with disabilities, the risk of having basic needs go unmet is substantial. A recent study found that, of the roughly three million people with disabilities living in the community who need assistance with eating, bathing and dressing each day, as many as one million do not get all the help they need. Of these individuals, 80 percent said they could not get dressed everyday, 30 percent said they soiled themselves because they had no other choice, and over 10 percent said they had gone to bed hungry at least once in the last month because they did not receive needed help with eating.¹¹

Gretchen Sidell's Story

In June 1999, Gretchen Sidell was just finishing a successful first year of high school in Illinois. She had maintained a 4.0 GPA, had developed close friendships, and things were “going great.” On June 13, she developed meningococcal meningitis and the next day she suffered a brainstem stroke that left her almost completely paralyzed. As she described later, “those moments changed my life forever.”

The stroke compromised Gretchen's every bodily function. She relies on a ventilator to breathe, a catheter to urinate, and a G-tube for nourishment. She requires constant monitoring to ensure that all systems are functioning properly and to identify and address potentially life-threatening problems.

Until her 21st birthday on December 2, 2004, the Illinois Medicaid program paid for 20 hours a day of nursing care through a waiver program for Medically Fragile, Technology Dependent Children. Despite the high cost of the nursing care, the state determined that it was less expensive to provide care to Gretchen in her home than to care for her in an institutional setting (both Gretchen's doctors and the state have determined that if she were moved into an institutional setting, the level of care she needs would require placement in a hospital). When Gretchen turned 21, she lost eligibility for services under the children's waiver. Under a separate waiver program for adults, the state paid for only 10 hours of nursing care a day, half of what Gretchen previously received. Her mother, who works full-time, provided or coordinated the remainder of the services.

After trying to manage Gretchen's care with the more limited funding, concern for her health and safety drove the family to sue the state Medicaid agency. The judge in the case ordered a temporary restraining order restoring reimbursement for 20 hours of nursing care. Gretchen's case will go to trial next year.

Despite significant medical challenges, Gretchen leads a full life at home. She can move her eyelids and mouth and communicates by blinking and mouthing words. With the help of her family and nurses, Gretchen attended classes for the remaining three years of high school and graduated with her class. She has enrolled at Illinois Community College. She sees her friends regularly, goes to movies, shops at the mall, and has even visited her sister in Chicago.

However, if the family does not win its case against the state, it will face an extremely difficult choice: continue to care for Gretchen at home with far fewer resources, potentially risking her health, or move her into an institution where all of her medical needs will be met and paid for. Her family is committed to keeping her at home, but the financial and physical strain will be enormous and their ability to provide the care Gretchen needs into the future is ultimately uncertain.

Increased Cost Burden

The loss of coverage for essential services can also impose a very high cost burden on young adults and their families. In an effort to maintain services no longer covered by Medicaid, young disabled adults and their families may try to pay for these services out-of-pocket. These out-of-pocket costs can be staggering and especially difficult to manage for young individuals just starting out in life and struggling simply to make ends meet.

Regardless of income and insurance status, people with disabilities experience higher health care cost burdens merely because of their greater need for health care services. Studies of health care utilization by people with disabilities all indicate they use services at much higher rates than those without disabilities. While lower cost sharing requirements in Medicaid serve to protect the disabled from excessive cost burdens; still, the financial burden can be substantial, especially when needed services fall outside the covered set of benefits. For poor adults with disabilities on Medicaid, out-of-pocket medical expenses consumed 5.6 percent of their family incomes in 2002, more than twice the percentage for non-disabled adults on Medicaid.¹² Changes in cost sharing requirements included in the DRA that allow states to increase the co-payment amounts for individuals with disabilities with incomes below 100 percent FPL will only increase the financial burden on these individuals.

Risk of Institutionalization or Having Needs Go Unmet in the Community

But, for these young people with severe physical and mental disabilities who had previously relied on personal care services or other similar services to continue living at home or in a community-based setting, the greatest risk in becoming an adult is not financial in nature; it is the threat of institutionalization, or of having basic health and daily living needs go unmet if they remain in the community without such services and supports. The Medicaid program has a bias in favor of institutional long-term care—two-thirds of Medicaid spending on long-term care services is for institutional care. Despite recent policy changes that have improved the availability of support in the home and in community-based settings, access to these services remains limited. And, without such services, many young adults have no other choice but to move into an institution or have some of their most basic needs go unmet while living in the community.

While states have expanded the availability of home and community-based services through federal Medicaid waivers, concerns over rising costs have caused states to limit the number of people eligible for these services. Many states have waiting lists for these services, some of which are years long. In 2004, there were nearly 207,000 individuals on waiting lists in 34 states.¹³ These waiting lists are a particular problem for programs targeting younger adults because turnover is minimal. Young adults with disabilities tend to stay in these programs for long periods of time, leaving few new openings at any given time.¹⁴ A strategy some states have adopted to address this problem is to place children who will likely need home and community-based waiver services as adults on waiting lists at ages as young as 14. By the time these children become adults they will have risen to the top of the waiting lists and will become eligible for the services.

Jessica Dybdahl's Story

Jessica Dybdahl is 23 years old and a student at Eastern Connecticut University. When she was 12, this athletic girl began to lose her balance and her ability to write neatly. The diagnosis was dystonia—a progressive neuro-muscular disease that strikes Jessica's body with painful spasms, making it difficult to walk and perform other everyday activities.

“Dystonia is like getting writer's cramp throughout out your entire body,” explains Jessica. To treat and ameliorate the impact of the condition, she gets physical therapy three times a week, medication and some medical equipment.

Jessica is fortunate in that as a student she is still covered by her parents' insurance plan. Her private health coverage is supplemented by Medicaid and Medicare Part D coverage for her medications. Still, Jessica and her family wage a constant battle against a broken health care system just to get the care she needs. That fight, Jessica fears, is tearing her family apart.

It is a struggle faced by many families in similar situations throughout the U.S. And, that struggle likely will get far worse for Jessica when she loses her private insurance coverage, possibly next year. As a child, her insurance was supplemented by comprehensive Medicaid benefits through her entitlement to EPSDT. However, as an adult, while she still qualifies for Medicaid, she will no longer have access to the full range of services she needs.

One service critical to Jessica's health and well-being that will not be covered by Connecticut's Medicaid program is physical therapy. After years of living in a wheelchair, Jessica is learning to walk again, thanks to deep brain stimulation performed while she was in a coma resulting from complications related to her disease. But, to continue gaining strength and mobility, she currently receives physical therapy three times a week. Without these visits, Jessica may lose her ability to walk, and with it, the new-found freedom that has enabled her to create an independent life for herself.

Despite her obvious anxiety, Jessica remains optimistic about her future. She hopes to go to medical school and become a doctor. Perhaps then, she can work to create a health care system that “avoids the battles for care people with disabilities face and allows families to be families.” To accomplish these goals, though, she needs continued access to vital health care services, something she may not be guaranteed if she is forced to rely solely on Medicaid for health coverage.

Provisions in the DRA seek to address the problem of limited availability of home and community-based services. Beginning in January 2007, states will be permitted to provide home and community-based services that previously could only be provided through a waiver as a state plan service. States will no longer be required to submit a waiver to provide these services, nor will they be required to demonstrate budget neutrality. In addition, the DRA provision eliminates the requirement that these services only be provided to individuals requiring an institutional level of care. In fact, states utilizing this option must adopt less restrictive eligibility requirements for community-based services.

The new DRA provision does not, however, address one of the key problems of existing HCBS waivers—that of waiting lists. In fact, the new law potentially exacerbates matters by establishing a new precedent in the provision of Medicaid services that allows states choosing to provide home and community-based services as a state plan option to establish enrollment caps and maintain waiting lists for these services. While this new provision has the potential to increase the availability of home and community-based services, continued reliance on enrollment caps may only increase the number of people on waiting lists.

Nick Dupree's Story

February 23, 2003 was a bittersweet day for Nick Dupree. It was the day he turned 21.

Nick was like a great many others his age. He went to Spring Hill College in Mobile, lived at home with his parents and younger brother, studied hard, maintaining an A grade point average, but mostly spent all his time surfing the internet, chatting with friends online, and listening to music. But in one respect he was very different from his peers. Nick was born with muscular dystrophy. He needed a power wheelchair to get around and a ventilator to breathe.

In 2000 and 2001, Nick was majoring in professional writing and hoping to begin his career at the Mobile Register. But he was also preoccupied with other matters. Nick along with his brother who has the same condition, was eligible for the EPSDT benefit in Alabama. For Nick, this meant receiving about 18 hours of personal care services a day to clean his trachea and make certain that his ventilator functioned properly. However, Nick would lose access to these essential personal care services when he turned 21 and became an adult in the eyes of the Alabama Medicaid program because these services were not covered for adults.

Concerned that without access to needed personal care services his only option would be placement in a nursing home, Nick took matters into his own hands. He organized a nationwide online campaign to force Alabama to continue to provide necessary services and supports to young people who age out of EPSDT and are at risk of being institutionalized. He worked with his state legislators to draft legislation to achieve this aim, gave interviews, and did anything else he could think of to focus attention on the issue.

Despite these efforts, the state continued to assert that the policy would not change. With weeks left before his 21st birthday and no other options, Nick sued the state under the Americans with Disabilities Act for violating his and others' civil rights.

In the face of intense pressure, the state applied for and received a waiver to provide home and community-based services to Nick and 25 other ventilator-dependent young people. With only days to spare, Nick was guaranteed continued access to services that would keep him out of a nursing home.

Reflecting back on what was achieved, Nick observes "I am safe, and no one in my exact situation will have to face a deadline looming on their lives at age 21 again. That is great news, but, at best, my victory only puts a band-aid on a sucking chest wound. This waiver only applies to those on ventilators who apply before turning 21. All those without home respirators and those who turned 21 before the waiver started get nothing, not to mention all those in other states. Many are falling, and will continue to fall, through our nation's Swiss cheese safety net."

Conclusion

Through EPSDT, Medicaid has played a special role for low-income children, especially those with disabilities. However, maintaining support for needed services as children become adults is a key concern. The restricted availability of services that enable young adults with disabilities to live in their homes or in other community-based settings limits the opportunity for these individuals to work and to lead as normal a life as possible. Without supportive services, many young adults with disabilities find it difficult to attend college and obtain and keep a job. The obstacles to education and employment compound the financial burden attributable to their disability.

The recent Medicaid changes through the DRA offer states an opportunity to increase the availability of these supportive services by providing enhanced benefits for targeted populations that are not offered to the general Medicaid population. One state, Kansas, has already taken advantage of this new flexibility to provide personal assistive services to adults participating in the Ticket to Work program for the working disabled. Following Kansas' lead, other states could target similar supportive services to disabled beneficiaries, including young adults aging out of EPSDT.

The current shift in Medicaid policy away from institutional care and toward a greater emphasis on community-based support options for people with disabilities represents an important step toward increasing access to needed services. Providing all adults, but young adults in particular, with needed health and supportive services helps to promote their independence and workforce participation, enabling them to participate more fully in public life.

ENDNOTES

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