

GOING FORWARD, MEDICAID POLICY MUST —

STATEMENT OF PRINCIPLES

- ◆ Reaffirm that eligible individuals with intellectual and other developmental disabilities are entitled to the full range of Medicaid health care and long-term services across their life span, including children's Early and Periodic Screening, Diagnosis and Treatment services
- ◆ Embrace the principle that people with intellectual and other developmental disabilities must be supported to live regular lives in the community, experience a high quality of life and, as adults, achieve economic security and personal independence
- ◆ Affirm that all children belong with families and the family knows what's best for the child
- ◆ Support families in their efforts to achieve independence and community inclusion for their sons and daughters with disabilities
- ◆ Expand access for children with disabilities to vital Medicaid benefits by enacting the Family Opportunity Act and establish the goal of extending essential Medicaid health care benefits to adults with disabilities up to 100 percent of poverty
- ◆ Guarantee that every eligible individual who needs essential day-by-day home and community services receives them promptly and confirm that individuals have the authority to control how services are provided
- ◆ Redirect Medicaid spending from institutional to home and community services by doing away with current funding silos and providing that money follows the person from an institution to a community-based setting
- ◆ Establish positive incentives for the cost-effective delivery of services so that all eligible individuals have equal access to services
- ◆ Provide for the effective coordination of the delivery of health care and long-term services
- ◆ Ensure that individuals are free from abuse, neglect and exploitation, enjoy their full rights as Medicaid beneficiaries and citizens, and experience quality of life through the operation of effective federal-state beneficiary protections, continuous oversight and quality monitoring/improvement systems
- ◆ Contribute to the quality and effectiveness of services through the development of a fairly compensated, well-trained, stable community workforce and a sufficient supply of qualified service providers
- ◆ Mandate that people with disabilities and families are co-equal partners in Medicaid policy making at the federal and state levels
- ◆ Ensure that individuals and families have understandable and easily obtainable information about Medicaid services and are supported in accessing the services that they need
- ◆ Recognize that the operation of effective and responsive service delivery systems requires state and local capacity to meet the needs of people in crisis, connect individuals to other public and private services, and continuously foster improved quality of life

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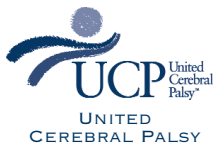
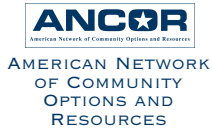


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THE ALLIANCE FOR FULL PARTICIPATION HAS JOINED TOGETHER TO CREATE A STATEMENT OF PRINCIPLES THAT MUST GUIDE THE FORMULATION OF FUTURE MEDICAID POLICY AT THE FEDERAL AND STATE LEVEL.

TOGETHER WE PLEDGE OUR SUPPORT OF THESE PRINCIPLES. WE WILL WORK IN CONCERT TO ENSURE THAT THESE TENETS ARE INCORPORATED INTO FUTURE MEDICAID POLICY.

FOR MORE INFORMATION, OR TO SIGN OUR PETITION IN SUPPORT OF THESE PRINCIPLES, PLEASE VISIT OUR WEBSITE.

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MEDICAID GOING FORWARD

Medicaid is a crucial lifeline for more than 1.8 million individuals of all ages with intellectual and other developmental disabilities who need comprehensive health care across their lifespan. Over one-half million of these individuals also rely on Medicaid long-term services for vital daily assistance. Without Medicaid, neither they nor their families would be able to afford essential health care and long-term services.

All people with disabilities that significantly impair their functioning should have the supports and services that they need in order to live healthy and productive lives in the community. Today, Medicaid funds essential services and supports that help Medicaid beneficiaries with intellectual and other developmental disabilities achieve these goals. It is imperative that Medicaid continue to be a reliable source of funding for the health care and long-term services that these individuals need in order to be healthy and live, work, and learn in their communities. Yet, today, hundreds of thousands of individuals are waiting for services. Major, far-reaching changes must be made in Medicaid to effectively support the needs and aspirations of individuals of all ages and all types of physical, intellectual, and sensory disabilities as well as serious mental illnesses. These changes must be tied to broader national strategies to reform health care and long-term services for all citizens. Individuals with disabilities also must have reliable access to affordable housing and sufficient income support so that they are not condemned to extreme, life-long poverty.

MEDICAID FACTS

PERSONS WITH INTELLECTUAL AND OTHER DEVELOPMENTAL DISABILITIES

- ◆ Nationwide, there are about 4.5 million children and adults with intellectual (e.g., mental retardation) and/or other developmental disabilities (e.g., cerebral palsy, spina bifida, autism) – about 1.5 percent of the U.S. population. They all experienced disability before age 22 (often at birth) and their disabilities are lifelong.
- ◆ People with intellectual and other developmental disabilities have substantial functional limitations that significantly impede the performance of major life activities without assistance.
- ◆ The majority of these individuals live with their families or on their own. Only about 10 per cent receive services in publicly-funded residential settings. Over 700,000 individuals are supported by family caregivers who are over the age of 60.

MEDICAID BENEFICIARIES WITH DEVELOPMENTAL DISABILITIES

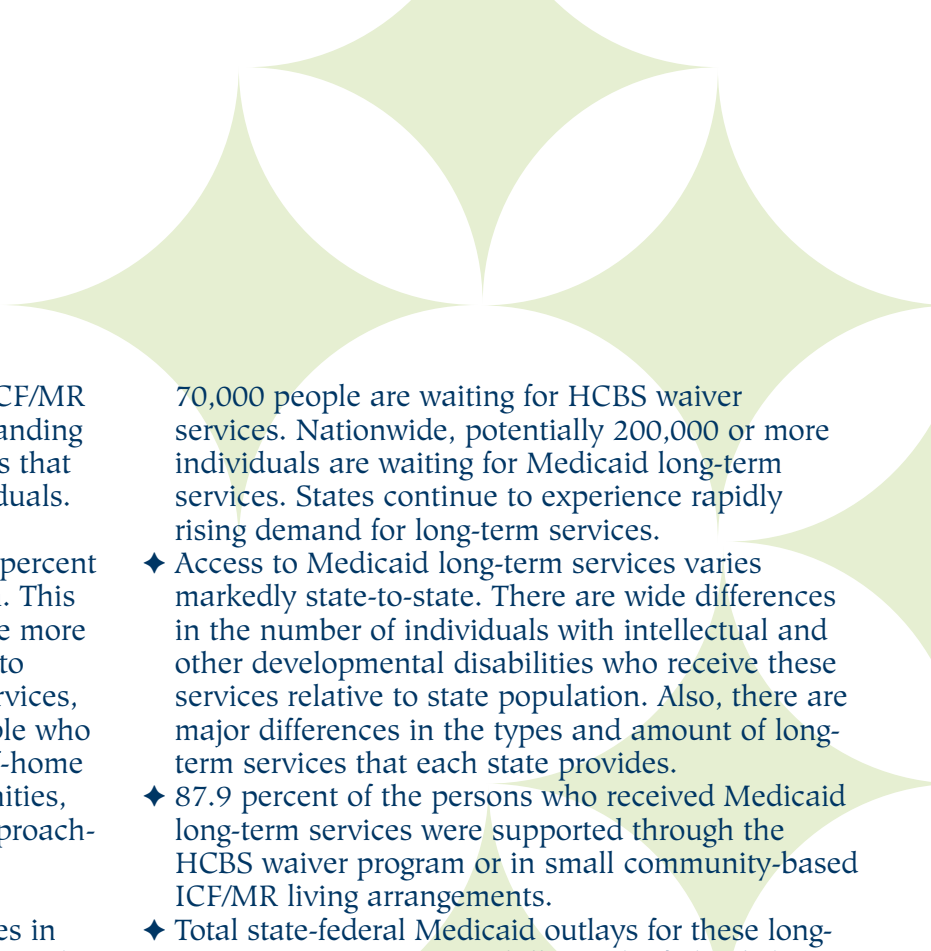
- ◆ There are an estimated 1.8 to 2.0 million Medicaid beneficiaries with intellectual and other developmental disabilities. They account for about 25% of all Medicaid beneficiaries who have disabilities. Less than one-half of all individuals with intellectual and other developmental disabilities are Medicaid beneficiaries.
- ◆ Eligibility for basic Medicaid health care benefits varies state-by-state. Only nineteen states extend Medicaid eligibility to people with disabilities with income up to the federal poverty line (\$9,570 in 2005). In most states, eligibility is limited to individuals whose income is well below the poverty line.
- ◆ Over one million Medicaid beneficiaries with intellectual and other developmental disabilities are children and adults who receive Supplemental Security Income (SSI) income assistance. Another one-half million qualify for Social Security Disabled Adult Children's (DAC) benefits. The Social Security Administration has determined that all of these individuals have major life-long disabilities and substantial functional limitations.
- ◆ Nearly all Medicaid beneficiaries with intellectual and other developmental disabilities are poor. The maximum Federal SSI benefit is currently pegged at 73% of the federal poverty level and is insuffi-

cient to meet daily living expenses. Only a small percentage of adults manage to secure employment to supplement their federal income assistance benefits. Child SSI beneficiaries live in low-income households. In most states, children with severe disabilities in moderate income households usually do not qualify for Medicaid.

- ◆ Medicaid is the sole source of health care for most of these individuals. Some adults receive both Medicaid and Medicare benefits. Adult Medicaid beneficiaries with intellectual and other developmental disabilities are too poor to afford private health insurance. Absent Medicaid, these beneficiaries would have no reliable health care.
- ◆ Child beneficiaries may be covered by their families' health insurance. But, private insurance usually does not cover the full range of benefits that these children need and can access through the Medicaid Early and Periodic Screening, Diagnosis and Treatment benefit.
- ◆ Neither Medicare nor the vast majority of private health insurance plans cover the types of ongoing long-term services that people with intellectual and other developmental disabilities need and can only obtain through Medicaid.
- ◆ Like other Medicaid beneficiaries, people with intellectual and other developmental disabilities often encounter serious problems in finding health and dental care providers who accept Medicaid. There is an acute shortage of Medicaid providers who have the skills to treat the frequently complex conditions experienced by these individuals, thus placing their health and well-being in jeopardy.

MEDICAID LONG-TERM SERVICES

Medicaid funds long-term services for more than 500,000 individuals with intellectual and other developmental disabilities, principally through the Intermediate Care Facility for the Mentally Retarded (ICF/MR) program and the Home and Community-Based Services (HCBS) waiver program. Eligibility for these programs is the same – a person must require significant personal and other assistance day-by-day. The HCBS waiver program permits a state to offer a wide range of services in the community to individuals who live with their families, on their own, or in other community living arrangements. But, states have the authority to cap the number of persons served through such waivers.



Over the past decade, the use of higher cost ICF/MR facilities has been scaled back in favor of expanding more flexible and cost-effective waiver services that yield demonstrably better outcomes for individuals. As a result, the average cost per individual of Medicaid long-term services declined by 18.3 percent between 1993 and 2004, adjusted for inflation. This system rebalancing has enabled states to serve more individuals. States also are taking other steps to improve the cost-effectiveness of long-term services, including providing increased services to people who live with their families in order to avoid out-of-home placements, expanding self-direction opportunities, and implementing new resource allocation approaches to better align dollars with needs.

Going forward, there are three major challenges in meeting the long-term services needs of people with intellectual and other developmental disabilities.

- ◆ First, the number of individuals who will need day-by-day supports is expected to grow by nearly 40 percent between 2003 and 2020. If services do not keep pace with this growth, tens of thousands more individuals will be forced to wait for critical long-term services.
- ◆ Second, in order to meet this increased demand, it will be necessary to recruit more than 300,000 direct support and other professionals – a daunting task because the available labor pool to fill these jobs will grow at a much slower rate than in past years. It will be impossible to recruit these professionals unless they are paid competitive wages.
- ◆ Third, it will be critical to reverse the continuing decline in the number of providers willing to furnish services and supports to individuals with intellectual and/or developmental disabilities and their families.

2004: FACTS AND FIGURES ABOUT LONG-TERM SERVICES

- ◆ Nationwide, 529,381 individuals with intellectual and other developmental disabilities received Medicaid long-term services, approximately twice the number in 1994.
- ◆ Despite the increase in the number of people receiving Medicaid long-term services, there are lengthy waiting lists for these services in nearly all states. In Florida, Louisiana and Texas alone, about

70,000 people are waiting for HCBS waiver services. Nationwide, potentially 200,000 or more individuals are waiting for Medicaid long-term services. States continue to experience rapidly rising demand for long-term services.

- ◆ Access to Medicaid long-term services varies markedly state-to-state. There are wide differences in the number of individuals with intellectual and other developmental disabilities who receive these services relative to state population. Also, there are major differences in the types and amount of long-term services that each state provides.
- ◆ 87.9 percent of the persons who received Medicaid long-term services were supported through the HCBS waiver program or in small community-based ICF/MR living arrangements.
- ◆ Total state-federal Medicaid outlays for these long-term services were \$27.4 billion. The federal share of these expenditures was \$16.3 billion. \$15.5 billion was spent on HCBS waiver services and \$11.9 billion on ICF/MR services. Adjusted for inflation, ICF/MR expenditures have not changed since 1994.
- ◆ Federal Medicaid outlays for long-term services to people with intellectual and other developmental disabilities represented 9.7 percent of total federal Medicaid expenditures for all types of services, about the same share as in 1997.
- ◆ Medicaid outlays for long-term services for people with intellectual and other developmental disabilities accounted for 30.7 percent of total Medicaid long-term services expenditures.
- ◆ The number of persons served in ICFs/MR declined by 26.5 percent between 1994 and 2004. However, a few states continue to rely too heavily on these facility-based services. During the same period, the number of persons supported through the more cost effective HCBS waiver program increased from 122,075 to 424,855 individuals.
- ◆ 43.4 percent of HCBS waiver participants with developmental disabilities lived with their families. Another 18.2 percent were supported in their own homes.
- ◆ The number of persons served in large ICF-MR funded state institutions fell by 37.1 percent between 1994 and 2004, declining to 41,653 persons. In 2004, fewer than 8 percent of all individuals who received Medicaid long-term services were served in these facilities compared to approximately 25 percent in 1994.