



#### Statement of the

#### Consortium for Citizens with Disabilities

# **Long Term Services and Supports Task Force**

#### to the

#### **Medicaid Commission**

July 11, 2006

### On Behalf of:

American Congress of Community Supports and Employment Services and Disability Service Providers of America Alliance

American Dance Therapy Association

American Network of Community Options and Resources

American Occupational Therapy Association

Association of University Centers on Disabilities

National Association of Councils on Developmental Disabilities

National Association of State Head Injury Administrators

National Down Syndrome Congress

National Mental Health Association

National Respite Coalition

Paralyzed Veterans of America

The Arc of the United States

United Cerebral Palsy

United Spinal Association

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The Consortium for Citizens with Disabilities is a coalition of national disability organizations working together to advocate for national public policy that ensures the self determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society. The CCD Task Force on Long Term Services and Supports (hereinafter "CCD") addresses issues concerning long term services and supports to individuals and families, including those provided by the Medicaid program, family supports, community living, employment supports, and other supports that enable individuals with disabilities of all ages to be independent and productive members of the community.

Medicaid is the nation's principal source of health coverage for low-income people. It covers more than 50 million Americans, including senior citizens, people with disabilities, children, and pregnant women. An overwhelming number of individuals of all ages who depend on Medicaid are very poor. Approximately 78 percent of Medicaid beneficiaries rely on federal Supplemental Security Income (SSI). Over 7 million people with disabilities of all ages rely on Supplemental Security Income (SSI). The maximum annual SSI payment in 2006 is \$7,236., with the average monthly SSI payment in May at \$452.80. Yet the 2006 federal poverty level (FPL) for an individual is \$9,800. Therefore, SSI payments are well below the FPL, at approximately 74 percent of poverty. Individuals relying on SSI have very limited incomes to meet the challenges of community integration -- housing, food, transportation, and supports.

For children with all types of disabilities, access to the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit, with its variety of screenings, services, and therapies, can often make a major difference in their lives. Access to these critical services is what enables them to lead healthy and more active lives; avoid additional disabilities; continue to live at home with their families; and make it through school. Children with disabilities also receive educationally related services such as occupational, physical, or speech therapies through Medicaid that help them succeed in school. These children grow up where they belong and can get jobs and be contributing members of society.

For people with epilepsy, mental illness, HIV, and a variety of other conditions, Medicaid is very often the only source of access to essential prescription drug coverage.

For people with a variety of physical disabilities, such as spinal cord injuries, traumatic brain injuries, cerebral palsy, or amputations, Medicaid usually is the only way they can get access to durable medical equipment like wheelchairs or prosthetic devices, as well as assistive technology.

For many people with cognitive and other types of disabilities, Medicaid generally is the only source of funds for them to live and work in the community with friends and families and avoid more costly and segregated nursing homes or institutions.

#### **Medicaid Works**

Medicaid has worked, and worked well, for more than 40 years. It has grown to be the program that provides needed health care and long term supports to 54 million people of all ages. It is also being called upon to help address the health care needs of 45 million

uninsured individuals. Medicaid supports the entire public and private health and long term care systems in this nation.

The Medicaid program not only works, it works efficiently. According to a recent national study, administrative costs for Medicaid were just under 7%; while private insurance administrative costs were almost double that at 13.6%. Due to the federal-state partnership, Medicaid also works to help boost state economies. Recent studies have illustrated how the Medicaid program helps generate business activities, jobs, and increased wages of employees in states.

Medicaid spending is not spiraling out of control. Medicaid spending has been increasing more slowly than the private market. From 2002-2004, per person Medicaid spending rose 6.7%, almost half the rate of the private market (12.5%) despite serving a sicker and needier population. Total U.S. health care spending growth slowed to 7.7 percent in 2003, compared to 9.3 percent growth in 2002. Analysis by economists at the Centers for Medicare and Medicaid Services (CMS) found that the deceleration of Medicaid spending was a key factor driving down the growth rate in overall U.S. health care spending. Medicaid spending growth between 2000 and 2003 was largely a result of external factors including the economic downturn that made many more people eligible for Medicaid and rapidly rising health care costs across the board, driven in large part by prescription drug prices and hospital costs.

Some policymakers suggest that lowering the provider payment rates is the answer to controlling costs. However, in an attempt to control state Medicaid costs in FY 2004, 49 states and the District of Columbia already cut or froze payment rates for at least one group of providers. Low provider payment rates limit the number of physicians and facilities willing to accept Medicaid beneficiaries as patients. Between 1997 and 2001, the percentage of physicians accepting any Medicaid beneficiaries as patients dropped from 87.1 percent to 85.4 percent. For many services, Medicaid reimbursement rates are actually lower than the cost of the service delivered.

# Medicaid and Long Term Care

Medicaid is also the primary public source of funding for long-term services and supports for people with disabilities of all ages. It is the largest funding source of state and local spending on mental health, mental retardation, and developmental disabilities services in the country.

The purposes of these services are directly in line with the purposes of the Medicaid program. As stated in Section 1901 of the Social Security Act, the funds made available for the Medicaid program are for the purpose of enabling each state "to furnish (1) medical assistance on behalf of families with dependent children and of aged, blind, or disabled individuals, whose income and resources are insufficient to meet the costs of necessary medical services, and (2) rehabilitation and other services to help such families and individuals attain or retain capability for independence or self-care..."

We particularly urge the Commission to focus on the second purpose of the Medicaid program: "rehabilitation and other services to help such families and individuals attain or retain capability for independence or self-care". Many of the services that provide long term

supports and that are often thought to have exceeded the medical purpose of the program are, in fact, well within the second stated purpose of the Medicaid program for helping individuals and families attain or retain capability for independence or self-care.

Currently, about 45 percent of the long-term care population is under the age of 65. Long-term supports are vital to individuals in this age range—especially in light of the fact that many may require supports over a lifetime. The vast majority of long-term care, over 80%, is delivered informally through family members, who are the backbone of our nation's long-term services system. The Medicaid program can play a vital role in providing family supports, such as lifespan respite care, to assist individuals with disabilities to remain at home and avoid costly and inappropriate institutional placements.

However, due to changing demographics and the increased lifespan of people with disabilities, there is an increasing number of aging caregivers who are providing lifelong care to their also aging relatives with disabilities. Regarding individuals with developmental disabilities, there are over 700,000 caregivers over 65 years of age. As these caregivers plan for the future care of their relatives, they face lengthy waiting lists for services and face agerelated declines and needs for their own long-term care. Waiting lists for long-term services and supports undermine the ability of families to plan for the future. Furthermore, the majority of younger individuals with disabilities want to live independently. Waiting lists and lack of community-based supports and services prevent individuals from having opportunities to live, work, and participate in their communities.

The number of elderly persons is projected to increase dramatically, both as a percentage of the population and in absolute numbers, due in part to the aging of the 77 million baby boomers and to increased life expectancy. The entry of baby boomers into the long-term supports and services system will place an additional burden on an already strained system.

It is unfortunate that policymakers frequently address the financing and delivery of long-term supports and services as if this was a need unique to the elderly. This singular focus has limited the options and type of supports and services offered to individuals of all ages. It is important to remember that there is a wide range in both the age and the nature of those in need of long-term supports and services and a need for an overall national policy on long-term care.

#### RECOMMENDATIONS

#### Recommendation: Maintain the Medicaid safety net.

Medicaid must remain the safety net for those individuals who need long term care but have no other source of financial assistance. We strongly urge the Commission to recommend that Congress maintain the individual's existing entitlement to Medicaid's full range of benefits and to the federal protections that make access to these necessary services and supports dependable and real.

The Medicaid program has become the nation's only publicly financed source of comprehensive long-term supports and services, supports that must also address various functional needs and supports that vary over a lifetime. In the absence of a comprehensive

national policy for long-term supports, Medicaid will remain the largest payer for long-term care. Congress must take steps to reduce the burden and fiscal pressure on the Medicaid program as the nation's only comprehensive approach to long term-supports.

Recommendation: Establish home and community based services as entitlement services with equal status and ease of access as facility based care.

Currently, approximately 67 percent of Medicaid dollars spent on long term care is spent on nursing homes and other institutional services, with only 33 percent spent for all home and community services, including home and community based waiver services, the personal care option, and home health services. Community services on average are less expensive than institutional services and are preferred by most individuals.

We urge the Medicaid Commission to recommend that Congress eliminate the institutional bias in Medicaid and focus on providing supports and services in home and community based settings. The statute should be changed to make community based services and supports part of the mandatory state plan services and such services should be based on individualized, person-centered home and community supports that offer flexible and expanded choices to address the lifetime needs of a diverse population. Sates should be required to develop a more stringent standard for eligibility for care provided in an institution.

The Commission has heard substantial testimony from beneficiaries and their families regarding the importance of Medicaid long term services in assisting beneficiaries to remain as independent as possible in the community. A clear message has been the need for eliminating the institutional bias in Medicaid and ensuring that people have equal access to community-based services.

The Deficit Reduction Act of 2005 (DRA) included Section 6086 which allows states to offer home and community based services as a state option. However, there are some problems with the language which must be amended in order to make the section useful to the states. We urge the Commission to recommend that Congress amend Section 6086 to authorize coverage of people up to 300 percent of the federal poverty level and to include all services and supports available under the HCBS waiver, including those covered under the "other" category.

Recommendation: Enact a broad-based long term care insurance program based on social insurance principles, freeing Medicaid for people who need it as a true safety net.

The Commission should include a set of recommendations based on the need for a comprehensive national approach to long-term supports that reduces the pressure on Medicaid as the single, largest funder of long-term care services and that expands the resources available for financing long-term supports.

Currently, there are few if any long-term care insurance products that will cover the comprehensive services needed by non-elderly individuals with severe disabilities. Once born with a disability, long-term care insurance is not an option to assist with the lifelong costs of long term supports. Because long-term care financing was never integrated into our national retirement and disability security systems, an unstable and convoluted patchwork

system of financing has emerged. Federal programs do not coordinate with or even complement private long-term care insurance. States provide long-term care as a public assistance program that helps seniors only after they have reached the poverty level while it restricts younger people with disabilities to a life of permanent impoverishment. Unless they have purchased long-term care insurance or have significant savings, the average family must try to piece together limited Medicare coverage, public services, and personal resources, until they spend down to Medicaid eligibility. A multi-faceted solution is needed. Public and private resources must be integrated into a flexible array of programs that can be adapted to provide appropriate levels of care at a reasonable cost.

In February 2001, Citizens for Long Term Care issued a report: *Defining Common Ground:* Long Term Care Financing Reform in 2001. Among other things, CLTC stated:

Most specifically, Citizens For Long Term Care agreed that there must be a new social insurance benefit that finances a minimum floor of financial protection for all. This benefit will be based on functional need with appropriate eligibility and benefit level standards and requirements. The new social benefit is to be combined with a program of tax incentives for the purchase of private insurance earlier in one's life. Citizens also strongly believes that public assistance must be available to those whose needs exceed all other public and private resources. The member organizations agreed that certain key elements should be a part of long term care financing reform.

One of the elements spelled out by CLTC was:

A new social insurance cash payment benefit with appropriate eligibility and benefit level standards and requirements must be based on the level of functional need and provide a minimum floor of protection in a way that is sufficiently flexible to best help disabled individuals and families meet their unique circumstances.

The members of the CLTC Board of Directors, listed as "guiding forces behind this paper" which "actively support and affirm its conclusions", were AARP, Aetna Inc., Alzheimer's Association, American Association of Homes and Services for the Aging, American Health Care Association, The Arc of the United States, National Association for Home Care, National Committee to Preserve Social Security and Medicare, and Service Employees International Union. Many other organizations joined the CLTC coalition in support of its goals, including many member organizations of CCD.

There is now significant interest on Capitol Hill for creating a national long term care social insurance program, financed through voluntary payroll deductions which would offer a vital source of support beyond the traditional entitlement programs and take pressure off of the Medicaid program. Senators Edward Kennedy (D-MA) and Mike DeWine (R-OH) have introduced the Community Living Assistance Services and Supports Act or CLASS Act (S. 1951). Those who become eligible for the CLASS Act benefits may be able to receive the support they need to remain as independent as possible and to avoid impoverishing themselves to receive Medicaid services, filling a major void in our national long term care system and helping relieve pressure on Medicaid as the primary payer of long-term care. Working individuals would enroll in the optional program and contribute monthly premiums into a trust fund. Enrollees would pay premiums for a minimum of 5 years before they could

become eligible for benefits. Payment of benefits would be based on functional disability needs. There would be no lifetime limits on benefits or underwriting that often excludes individuals with disabilities from purchasing long-term care insurance. In addition, benefits would be paid in cash and the bill specifically allows individuals to hire family caregivers if desired.

We urge the Commission to recommend that Congress enact federal legislation similar to the CLASS Act to establish a long term care insurance program, financed through payroll deductions, to provide long term supports based on functional need.

Recommendation: Address workforce, technology, and other global issues requiring investment.

Regarding workforce issues, we urge the Commission to make recommendations to Congress in the following areas:

- Encourage workforce retention through better wages/benefits. (Direct Support Professionals Act, H.R. 1264)
- Ensure reimbursement rates to providers based on individual need, rather than service model.
- Enhance supports for informal caregivers. (Community Living Assistance Services and Supports Act and Lifespan Respite Care Act (S. 1283/ H.R. 3248))
- Recommend elimination of the barriers to cost-effective home and community based services created by state nurse practice acts.

The lack of a stable, quality direct support professional workforce is a crisis that will plague the entire long-term care field in the 21<sup>st</sup> century unless national attention is brought to this issue. This crisis is a result of several factors, including the increased demand for long-term supports and services; a traditional labor supply not able to keep pace with demand; and jobs that cannot compete within today's labor market.

The cost of this labor comprises between sixty and seventy percent of the total dollars necessary to provide long-term supports and Medicaid is the nation's leading payer of these long-term supports. Yet this system inadequately reimburses providers to cover the cost of wages and benefits to attract, train, and retain quality workers. Our current financing system does not support today's wages, and therefore raises serious questions about the ability to recruit future direct support professionals.

There is a first step the Commission could take in addressing the workforce crisis that threatens the quality of supports to people with significant disabilities and undermines their ability to live in their own homes and communities. We urge the Commission to recommend passage of the Direct Support Professionals Fairness and Security Act of 2005 (H.R. 1264) introduced by Representatives Lee Terry (R-NE) and Lois Capps (D-CA).

In addition, Medicaid continues to reimburse providers based on a service model (ex., nursing facility vs. personal care) rather than based on individual need. This encourages the "open slots" approach to Medicaid planning at the state level rather than planning to meet the individual's actual need.

Informal caregivers, including friends and family, continue to take pressure off the Medicaid system while meeting the needs of individuals in home and community based settings. For such informal caregiving to be able to continue meeting the needs of many, families and other caregivers must be supported in their roles. The CLASS Act and the Lifespan Respite Care Act could both increase the supports families need to avoid turning to Medicaid.

Senators Hillary Clinton (D-NY) and John Warner (R-VA) introduced the Lifespan Respite Care Act (S. 1283) in the Senate and Reps. Michael Ferguson (R-NJ) and Jim Langevin (D-RI) introduced a companion bill (H.R. 3248) in the House. The Lifespan Respite Care Act would help to build coordinated systems of accessible, community-based respite care services for all caregivers of individuals regardless of the individual's age or disability. The Lifespan Respite Care Act would authorize funds for: (1) development of state and local lifespan respite programs, based on models and best practices; (2) evaluation of such programs; (3) planned or emergency respite care services; (4) training and recruitment of respite care workers and volunteers; and (5) caregiver training. The only major difference between the two bills is the authorizing appropriations language. The Senate bill is authorized at "such sums"; the House bill is authorized at \$90.5 million.

Finally, people with disabilities and caregivers have encountered numerous problems over the years in their attempts to remain independent due to "nurse practice acts" at the state level. These nurse practice laws often define what procedures must be performed by a nurse rather than a layman. In many cases, procedures which could be taught to caregivers are prohibited by the nurse practice acts, unless the individual or a family member performs the procedure. This forces many people into more costly settings where nurses are available. Furthermore, the state statutes vary widely. We urge the Commission to address this issue in its recommendations.

Regarding technology, we urge the Commission to make recommendations on the following:

- Systems/Administrative Improvements -- Investments in systems improvements are needed, including in the area of health care information and systems management.
- Assistive technology for individuals with disabilities Investments are needed in assistive technology which can assist individuals with disabilities remain or become more independent and help reduce long term care costs.

The Commission has discussed possible cost savings from increased use of technology in the states. In addition, the Commission should support increased use of assistive technology that can aid an individual in being more independent and productive.

Commissioners have heard testimony and noted that there are some related issues requiring attention in order for home and community service options to be fully successful. These include:

- Supplemental Security Income (SSI) benefits must be adequate to cover living expenses.
- Coordination with affordable and accessible housing is critical.

We urge the Commission to encourage Congress to address these important issues.

Recommendation: Encourage the use of quality outcome measures, including consumer satisfaction, and ensure real public participation in the development of waivers and state plan amendments.

Since the Medicaid program has such significant impact on the lives of people who must rely on its programs, we believe that the states must adopt quality assurance systems that ensure quality services, that assess consumer satisfaction, and that have in place feedback mechanisms to ensure immediate and appropriate resolution to problems when they arise. We urge the Commission to recommend that Congress require such quality systems for all services.

In addition, it is critical that states include all stakeholders in the development of state plan amendments and waivers from the initial stages of planning through final negotiations. We believe that such involvement must include real notice in advance of the planning process. We urge the Commission to recommend that Congress require that all waivers and state plan amendments be open to stakeholder and public participation.

We also urge that there be no blanket approval of Section 1115 waivers (authorized under Section 1115 of the Social Security Act, 42 USC 1315) or components thereof. These waivers have allowed states to test how changes in eligibility and coverage rules can achieve savings in and expand access to the Medicaid program and to test innovative approaches. CCD is concerned, however, that the knowledge gained through these experiments might not be used properly.

First, it is important to remember that these waivers were designed as time limited demonstration projects and not to be construed as permanent changes to state Medicaid plans. The purpose of the authority granted to the Secretary under Section 1115 is to allow changes to the federal Medicaid rules to be tested using states as laboratories without affecting the entire population of Medicaid beneficiaries. The effects of those changes should be evaluated and then, as with all demonstration projects, either adopted as changes to the Medicaid program as a whole, or found to be ineffective or harmful and no longer pursued.

It is also important to ensure that any changes or reforms made to the Medicaid program based on these experiments only be made after the completion of rigorous analysis of the effects of the waiver on the beneficiaries in the state. CCD is concerned that such evaluation is not being completed at this time, especially in relation to the effects such waivers have had on people with disabilities receiving Medicaid. Since CCD is a coalition with members representing people with a wide variety of disabilities, it is very clear that each of the waivers in place can have a disparate effect on people with different health care needs.

For example in the soon to be implemented Florida waiver, Medicaid recipients will be given a voucher containing a risk-adjusted allotment of funds with which to purchase coverage through a health care plan. Private health care plans will be given broad discretion in the coverage of so-called optional services, which are essential disability services and include a range of community living services such as physical and occupational therapy, personal care, and rehabilitation services. It is possible for private plans to meet all state sufficiency of benefit requirements while still not covering essential medically necessary services or by severely limiting the amount, duration, and scope of these critical benefits. Once an adult,

including an adult with a disability, reaches their annual benefit limit they will be responsible for all health care costs. It is likely that many adults with disabilities will exceed their risk adjusted cap and will not have the income to pay for the additional care they may require. It would be unwise to allow Florida to permanently implement this change, or to make this change to the Medicaid program as a whole, without completing a thorough analysis of the effects on all of the populations of these rule changes.

## Recommendation: Ensure that Medicare pays its full share for dual eligibles.

Currently, 42 percent of Medicaid spending is for services for people who are eligible for Medicare. In relation to the nearly 7 million individuals who are eligible for both Medicare and Medicaid (dual eligibles), Medicaid should be restored to its role as the payer of last resort. This includes increased federal Medicare support for prescription drug coverage, durable medical equipment, and long-term care services for low-income persons eligible for both Medicaid and Medicare. We urge the Commission to recommend that Medicare assume the cost of long-term services and supports, Medicare premiums, and Medicare co-payments for dual eligibles. These costs should be born either by reforms to Medicare and/or creation of new public and private long-term care financing mechanisms.

Furthermore, the two-year waiting period for Medicare eligibility for people with disabilities under age 65 creates a severe financial strain on the individual as well as on the Medicaid program (for those who impoverish themselves during the two-year period). Medicare coverage of these Title II beneficiaries as soon as they become eligible for Title II would help many to avoid exhausting resources which they will need in the coming years. We urge the Commission to recommend that Congress eliminate the two-year waiting period for Medicare for Title II beneficiaries with disabilities under age 65.

#### Conclusion

CCD recognizes the need to address rising long term care costs that face our nation. It is important to note, however, that Medicaid's overall growth rate is lower than that of private health insurance premiums and that there is no comparable private long term care resource with which to compare. Cutting or capping the Medicaid program, rather than addressing underlying costs and the growing demand for long-term care, will have profound consequences not just for those who rely on Medicaid but for the overall health care system.

We ask that any Medicaid long term care reform proposal protect both the funding and current structure of the program so that it may continue to meet the vital health care needs of the most vulnerable beneficiaries. CCD thanks the Commission for this opportunity to add our voice to your consideration of very important issues. This statement has focused on long term care issues since the Commission has recently dedicated two Commission meetings to long term care issues. The CCD Health Task Force may submit a separate statement later which focuses on other health care issues facing people with disabilities in the Medicaid program.

Summary of Recommendations for Medicaid Long Term Services and Supports Consortium for Citizens with Disabilities, Task Force on Long Term Services and Supports

July 11, 2006

### Federal/State Medicaid Program

Recommendation: Maintain the Medicaid safety net.

- Maintain the individual's existing entitlement to Medicaid's full range of benefits and to the federal protections that make access to these necessary services and supports dependable and real.
- Reduce the burden and fiscal pressure on the Medicaid program as the nation's only comprehensive approach to long term-supports.

## **Home and Community Based Services and Supports**

Recommendation: Establish home and community based services as entitlement services with equal status and ease of access as facility based care.

- Eliminate the institutional bias in Medicaid and focus on providing supports and services in home and community based settings.
- Amend Section 6086 to authorize coverage of people up to 300 percent of the federal poverty level and to include all services and supports available under the home and community based services waiver, including those covered under the "other" category.

### **Long Term Care Insurance**

Recommendation: Enact a broad-based long term care insurance program based on social insurance principles, freeing Medicaid for people who need it as a true safety net.

 Enact federal legislation similar to the Community Living Assistance Services and Supports Act or CLASS Act (S. 1951) to establish a long term insurance program, financed through payroll deductions, to provide long term supports based on functional need.

#### Investment/Global Issues

Recommendation: Address workforce, technology, and other global issues requiring investment.

Regarding workforce issues:

- Encourage workforce retention through better wages/benefits. (Direct Support Professionals Act, H.R. 1264)
- Ensure reimbursement rates to providers based on individual need, rather than service model.
- Enhance supports for informal caregivers. (Community Living Assistance Services and Supports Act (S. 1951) and Lifespan Respite Care Act (S. 1283/ H.R. 3248))
- Eliminate the barriers to cost-effective home and community based services created by state nurse practice acts.

### Regarding technology:

• Invest in systems/administrative improvements including health care information and systems management.

• Invest in assistive technology for individuals with disabilities.

#### Regarding related issues:

- Supplemental Security Income (SSI) benefits must be adequate to cover living expenses.
- Coordination with affordable and accessible housing is critical.

#### Quality

Recommendation: Encourage the use of quality outcome measures, including consumer satisfaction, and ensure real public participation in the development of waivers and state plan amendments.

- Require that states adopt quality assurance systems that ensure quality services, that
  assess consumer satisfaction, and that have in place feedback mechanisms to ensure
  immediate and appropriate resolution to problems when they arise.
  - Require that all waivers and state plan amendments be open to stakeholder and public participation from the initial stages of planning through final negotiations, including real notice in advance of the planning process.
- Prohibit blanket approvals of Section 1115 waivers (authorized under Section 1115 of the Social Security Act, 42 USC 1315) or components thereof. Ensure rigorous analysis of the effects of the waiver on the beneficiaries in the state.

### **Dual Eligibles**

Recommendation: Ensure that Medicare pays its full share for dual eligibles.

- Ensure that Medicare pays its full share for dual eligibles, assuming the cost of long-term services and supports, Medicare premiums, and Medicare co-payments.
- Eliminate the two-year waiting period for Medicare for Title II beneficiaries with disabilities under age 65.

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- Eliminate the two-year waiting period for Medicare for Title II beneficiaries with disabilities under age 65.