

**TESTIMONY OF
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ON
THE NEW FREEDOM INITIATIVE
BEFORE THE
SENATE FINANCE COMMITTEE
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Chairman Grassley, Senator Baucus, distinguished Committee members, thank you for inviting me to discuss the Medicaid legislative proposal under the New Freedom Initiative. The New Freedom Initiative is President Bush's plan to ensure that individuals with disabilities have the opportunity to live independently in their communities. As part of the initiative, the President asked relevant Federal agencies, including agencies within HHS, to evaluate their policies, programs, statutes, and regulations to determine whether they should be revised or modified to improve the availability of community-based services for qualified individuals with disabilities, so they may live with the respect and dignity independent living brings. While New Freedom is a government-wide initiative, I will focus specifically on the Medicaid provisions that require statutory changes in order to implement it.

Medicaid Spending on Home and Community-Based Waivers

Medicaid is a vital resource of financial support for community living. More than 800,000 individuals are served through home- and community-based waivers. State and Federal expenditures have increased from \$13.9 billion in FY 2001 to an estimated \$20.7 billion in FY 2004.

Between 2001 and 2004, a total of \$68.7 billion will be spent under home- and community-based waivers. More money has been spent in those four years than was spent during the previous eight years (\$56.6 billion). Over the same period, care expenditures for state plan service grew, from \$5.25 billion to \$7.95 billion, a 51 percent increase.

New Freedom Initiative in the FY 2005 Budget

CMS remains committed to identifying and eliminating obstacles faced by those with disabilities. To further enhance the opportunities for people to live meaningful lives in the community, the President included support for the New Freedom Initiative in his FY 2005 budget proposal. The budget authorizes approximately \$428 million in FY 2005 and approximately \$2.2 billion over 5 years to improve community services, help transition people out of institutions, and support Americans in the community through a variety of initiatives.

Money Follows the Individual

Our message is simple and clear. We believe individuals and families make better decisions for themselves than the current institutional-based, provider-driven systems. In 2001, 71 percent of Medicaid funds for long-term support for seniors and people with disabilities were spent on institutional services. While states are making efforts to develop infrastructures designed to support community-based services, progress in reducing dependence on institutional care has been difficult to achieve due to the fiscal challenges states are facing. The Money Follows the Individual Rebalancing Initiative is a \$1.75 billion, five-year demonstration program to help Americans with disabilities transition from nursing homes or other institutions to community living. The initiative will help states achieve a more equitable balance between the proportion of total Medicaid spending on institutional services and the proportion of funds used for community-based support in their state plans and waivers. The initiative also will help States design flexible financing systems for long-term supports that allow funds to move with the individual to the most appropriate and preferred setting as the individual's needs and preferences change.

To assist individuals who move voluntarily from a Medicaid-certified institution to the community, the initiative will pay for one year the full cost of home and community-based services for each individual moved from institutional care to a package of home and community-based services. At a minimum, the package of services must be equivalent to the services that a state could provide under a Medicaid waiver. After the

demonstration year, the state would agree to continue such care at the regular Medicaid matching rate and agree to maintain a balance between institutional and community-based services in their long-term care systems. States will be required to develop a multi-year plan that includes specific action steps to redesign funding arrangements to implement the principles of money follows the person and reduce reliance on institutional forms of Medicaid service. The plan also must identify steps to increase the infrastructure for community services and improve the ability of individuals to live and participate in their communities.

The President's commitment to the New Freedom Initiative budget proposal has not changed. The President's FY 2005 budget proposes the authorization of \$1.75 billion over five years for the Money Follows the Individual Rebalancing Demonstration. While we recognize that the Budget in Brief that was published on the web shows budget outlays of \$0 in FY 2005 and \$500 million over 5 years we should not confuse proposed budget authority with estimated outlays.

While CMS will award a total of \$350 million a year in grants for each year of the initiative (FY 2006- FY 2009), we anticipate that States will likely spend their awards slowly over the course of their 5-year project periods. As a result of this assumption, CMS estimated smaller initial outlays to States.

The outlay estimate also takes into account our assumption that CMS will need time to develop a solicitation, review proposals, and award the demonstration grants. Awards are likely to be made close to the end of the fiscal year, and as a practical matter given the timing of awards, states will likely begin to draw down funds at the beginning of FY 2006.

LIFE Accounts

The President's budget proposes the Living with Independence, Freedom, and Equality (LIFE) Account Savings Program as the next improvement in the home- and community-based system. LIFE Accounts will be personal savings accounts owned and directed by

the individual. At no cost to the federal government, LIFE Accounts will remove barriers to independence, community living, and participation in the labor force for Medicaid-eligible individuals with disabilities by giving them the opportunity to build savings for purchases that will increase their independence and productivity while also maintaining their vital health coverage and standard of living.

Currently, individuals who live in states with a CMS Independence Plus waiver are permitted to direct their own long-term supports in order to delay institutional or other high-cost placement outside their community. In states with such programs, individuals may direct and control their own supports within the bounds of an individualized budget established in agreement with the relevant state agency. States that have programs built on this concept encourage high-value, cost-effective decision-making. Independence Plus waivers have built on the very successful “Cash and Counseling” waiver.

Under the President’s proposal, individuals who self-direct all of their Medicaid, community-based, long term supports will have the opportunity to place up to 50% of the savings from their self-directed Medicaid community-based service budget into LIFE Account at the end of the year. Earnings from employment and limited contributions from others may be used in the LIFE Accounts to align the amount in the fund with the level of need.

To prevent the assets in a LIFE Account from jeopardizing an individual’s ability to qualify for other forms of assistance, income and resources in the accounts will not be considered when making a determination for a state’s Medicaid program or any federal assistance program. LIFE Account income and assets will not be considered in establishing benefit levels under those programs for either the account holder or for any members of the account holder’s immediate family.

New Freedom Demonstrations

The President’s FY 2005 budget proposal also includes a number of other investments in the New Freedom Initiative. Three innovative demonstrations will enhance the ability of

individuals with disabilities to live and fully participate in the community. These demonstrations support:

- Respite services to caregivers of adults with disabilities
- Respite services to caregivers of children with severe disabilities
- Home- and community-based services for children residing in psychiatric residential treatment facilities.

With \$18 million proposed for FY2005 (and \$327 million over five-years), these demonstrations will test the provision of respite for caregivers of adults as a Medicaid service, the provision of respite for caregivers of children with substantial disabilities as a Medicaid service, and the provision of family- and community-based programs for children with psychiatric disabilities as an alternative to psychiatric residential treatment facilities.

Other proposals in the President's FY 2005 budget are designed to provide flexibility to families and States.

- *Spousal Exemption* – Under current law, if an individual is Medicaid eligible and that individual's spouse participates in the section 1619(b) program – a Supplemental Security Income work incentive program, the spouse's earnings could cause the individual to lose his or her Medicaid. The President's budget proposes to protect the Medicaid coverage of an individual married to a disabled individual participating in 1619(b).
- *Presumptive Eligibility* – To reduce the prevalence of individuals entering nursing facilities from hospitals due to the length of time required to determine Medicaid eligibility for home and community-based services, the President has proposed to offer States the option of providing those individuals who need Medicaid home- and community-based care with services for up to 90 days while Medicaid eligibility is being determined. Under this proposal, the Federal government will pay its share of the first 90 days of community services whether or not the individual is ultimately deemed Medicaid-eligible.

- *Direct Service Community Workforce Demonstration* – Proposes \$3 million in discretionary funds to continue a demonstration to increase recruitment and retention of direct care service workers including an emphasis on the provision of a health care benefit for the workers.
- *Real Choice System Change Grants* – Proposes \$40 million in discretionary funds to continue assistance to States in developing systems that support community-based care alternatives for people of all ages with disabilities.

Existing CMS Initiatives

The President's FY 2005 budget proposal builds upon a number of accomplishments that have been achieved since the President signed an Executive Order on June 18, 2001, directing Federal agencies to "tear down the barriers" to community living for individuals with disabilities. This order called for a government-wide framework to provide the elderly and people with disabilities with the support system necessary to choose where they want to live and to participate fully in community life. CMS has been working diligently on the initiative to eliminate the obstacles facing people with disabilities who want to live and work in their communities.

Real Choice System Change Grants

Since 2001, CMS has awarded approximately \$158 million (FY 2001-2003) in grants to help states and others develop programs that allow people with disabilities or long-term illnesses to live meaningful, productive lives in the community. These grants are intended to foster the systemic changes necessary to allow those with disabilities to access quality services from their choice of providers in accordance with their living preferences and priorities. For example, a number of states, including Maine and Pennsylvania, received grants for "Money Follows the Person" research and demonstration programs in FY 2003. These particular grants helped States to determine what infrastructure and policy changes would be required to rebalance their long-term support systems and to implement the principles of money follows the person. Also in FY 2003, CMS funded feasibility study grants in areas that are included in the President's

FY 2005 budget, including respite for adults, children, and alternatives to community-based treatment for children.

Independence Plus Initiative

In 2002, CMS launched the Independence Plus Initiative to afford Medicaid participants increased choice and control that results in greater access to community living. The Independence Plus Initiative expedites the ability of states to request waiver or demonstration projects that give individuals and their families greater control over their own services and supports.

Currently there are five Independence Plus Programs, including four 1915(c) waivers (New Hampshire, Louisiana, South Carolina and North Carolina), and one 1115 Demonstration (Florida). The Independence Plus programs allow participants to design a package of individualized supports, identify and attain personal goals, and supervise and pay their caregivers.

Florida's Independence Plus Program, funded through CMS' 1115 demonstration authority, was recently recognized with a grant from the Social Security Administration to expand the impact of the program. The new collaborative program, named the Florida Freedom Initiative, will waive certain SSI rules to test whether the combination of Medicaid and Social Security waivers will foster greater self-sufficiency among the SSI and CMS beneficiaries who participate in the demonstration.

Additionally in FY 2003, CMS awarded 12 grants to states under the Real Choice Systems Change grant opportunity to help states design self-directed waiver and demonstration programs. These "Independence Plus" grantees are: Connecticut, Colorado, Florida, Georgia, Idaho, Louisiana, Massachusetts, Maine, Michigan, Missouri, Montana, and Ohio.

CMS Action Plan for Quality

CMS has taken a multi-faceted approach to addressing quality of care issues in home and community-based services. Earlier this year, Secretary Thompson submitted to Senators Grassley and Breaux an updated report on *CMS's Action Plan for Quality in HCBS*. The *Action Plan* provides a status report on the quality initiatives that CMS has undertaken in Medicaid home and community-based services. I am pleased to inform the Committee that the majority of the actions (16 of the 18 promised actions) to which we committed have been completed. We have made substantial progress on the other two. One example of our success in this area was the development of the *Quality Framework*, a guide to provide states with a uniform national format to describe the key components of their quality assurance and quality improvement programs. We intend the *Quality Framework* to serve as a common frame of reference. CMS also has worked with a variety of key stakeholders, subject matter experts, and consumers to complete a national inventory of state quality assurance and improvement strategies and provide technical assistance to states to assist them in redesigning their quality management systems.

Additional Accomplishments

CMS has made progress on a number of other fronts through the New Freedom Initiative. This year, CMS awarded a total of \$15.7 million in grants to 28 States and the District of Columbia to help people with disabilities keep and find work without endangering their health benefits as part of the Ticket to Work and Work Incentives Improvement Act.

CMS also funded approximately \$6 million in grants to improve the recruitment, training, support, and retention of direct service workers in FY 2003. For FY 2004, CMS plans to fund additional grants to States and others at the same level of support.

Recognizing the importance of providing information to and receiving input from key stakeholders, CMS holds Open Door Forum teleconferences on the New Freedom Initiative to discuss possible reforms that could remove barriers to community living and participation of those with disabilities. Last year, 2,519 people participated in 9 forums.

Conclusion

Chairman Grassley, Senator Baucus, and members of the Committee, thank you again for the opportunity to speak to you today about the New Freedom Initiative, a nationwide effort to remove barriers to independent, community living for people of all ages with disabilities and long-term illnesses. The President is committed to helping people with disabilities exercise more control over all aspects of their lives, including the supports they receive and where they live. This commitment is critical to helping people with disabilities achieve the freedom and independence they deserve. The New Freedom Initiative represents an important step in working to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, and live with the dignity and respect that comes with full participation in community life. Thank you again for this opportunity, and I look forward to answering any questions you might have.