DEPARTMENT OF HEALTH & HUMAN SERVICES
Centers for Medicare & Medicaid Services
Room 303-D
200 Independence Avenue, SW
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Public Affairs Office

Opening Doors to Independence:
CMS Accomplishments in Support of the Presidential New Freedom Initiative

For many Americans, health care coverage is more than a question of access—it is a question of access to *appropriate options and services* for oneself or a family member. The President's New Freedom Initiative, announced in February 2001, called for a comprehensive assessment of federal policies, programs, statutes, and regulations to identify barriers that impede community living for disabled individuals—and for recommended solutions. On the eleventh anniversary of the Americans with Disabilities Act, the Secretary noted*, "We need to keep working to open the doors to independence."* Indeed, since 2001, CMS has been aggressively opening these doors using a variety of approaches, programs, and funding sources.

In addition to the $30 million in Real Choice Systems Change Grants announced today to help develop programs for people with disabilities or long-term illnesses—these dollars are *in addition to* the 188 grants for over $158 million to 49 states and the District of Columbia between fiscal years 2001 and 2003--**CMS has also launched number of other critical initiatives in direct support of this Presidential priority.**

LIFE Accounts— The Next Leap Forward in Home & Community Based Services

The President's 2005 budget proposes the Living with Independence, Freedom, and Equality (LIFE) Account Savings Program as the next revolution in the home- and community-based system. CMS envisions LIFE Accounts as 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 critical health care coverage and standard of living.

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.

In order to encourage our state partners to explore this "ownership" option for disabled individuals and their health care, CMS included in the current Real Choice Systems Change solicitation funding for states to conduct studies assessing the feasibility of developing LIFE Account savings programs. CMS will be able to make these investments in both Wisconsin and New Hampshire. Using the Federal grant funds, those states may hire staff and/or contractors to assist in research, planning activities, and the creation of documents. CMS believes these studies will be a significant first step in implementing an important new Presidential proposal.

Services in the Home and Community: Independence Plus & Other Community-Based Services

CMS' efforts to "open doors" are exemplified in our Independence Plus waiver initiatives, which encourage individual or family-direction of supports and services that keep people in the community. Rather than encouraging placement that does not always serve the best needs of individuals—such as institutionalization—*Independence Plus*, announced on May 9, 2002, gives individuals more control over the selection of services that affect the health care of themselves or that of a family member. By placing this power in the hands of individuals and/or their families, CMS has increased personal autonomy while promoting rational, cost-effective decision-making about supports and services, rather than encouraging dependence and over-reliance on institutional care. We have begun the process of implementing Independence Plus through a major demonstration project in Florida and new home and community-based services waivers in Louisiana, New Hampshire, North Carolina and South Carolina. The *Independence Plus* and other "Self-Directed" Waiver Programs involve ten states serving approximately 64,000 individuals who are have the option to self-direct their care. These innovative self-direction programs are in addition to 280 other home and community-based waiver programs in almost all states across the country.

Medicaid's home and community-based waivers are a vital funding resource for community living. 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 to support home- and community-based waivers. More money has been spent in those four years than was spent during the previous eight years combined ($56.6 billion); it is clear that CMS and our state partners have in recent years made great strides in ensuring people receive the care they need *where* they want to receive it. Over the same period, care expenditures for related state plan services supporting community living grew as well, from $5.25 billion to $7.95 billion. This growth represents a remarkable 51 percent increase.

Partnership Between CMS and AoA: Establishment of Aging and Disability Resource Centers.

In fiscal years 2003 and 2004, CMSO awarded 24 grants totaling $19 million to create "one stop" Aging and Disability Resource Centers to help consumers learn about and access long-term supports, ranging from in-home services to nursing facility care. This program is funded and administered through a partnership between the CMS and the Administration on Aging (AoA):

- The 2003 Centers are located in Louisiana, Maryland, Massachusetts, Maine, Minnesota, Montana, New Hampshire, New Jersey, Pennsylvania, Rhode Island, South Carolina, and West Virginia. Grant funding provided the ability to have resource centers in two to eight counties in

- 2004, and by 2005 New Hampshire, Pennsylvania, and Rhode Island will have Centers throughout their states.
- The 2004 grants were awarded to state and territorial agencies in Alaska, Arkansas, California, Florida, Georgia, Illinois, Indiana, Iowa, New Mexico, North Carolina, Northern Mariana Islands, and Wisconsin. These Centers will be operational by Fall 2005.

Addressing the Shortage of Direct Service Workers

CMS created a demonstration program in 2003 to make direct grants to states to address the increasing shortage of direct service workers. These workers are the backbone of the community-based long-term care system and having a large enough direct service workforce in place is integral to providing the volume and quality of care needed by elderly and disabled Americans. In fiscal years 2003 and 2004, CMSO awarded 10 grants, totaling over $11 million. Six grantees received $1.4 million, and five of these grantees will offer health insurance to direct service workers, testing whether that incentive assists in keeping workers in their positions for longer periods. Two other grantees received $680,000 for developing educational materials, training of service workers, mentorship programs and other activities.

Supporting the Workforce Participation of Workers with Disabilities

A disability should not deter any American from being able to contribute their skills and talents to the country's workforce-- and the need to keep health care coverage should never be an incentive to remain outside of the workforce.

At a time when state funding for innovation is very limited, the **Medicaid Infrastructure Grant (MIG) program** provides funding to states to build the necessary program supports to working individuals with disabilities, and supports the establishment of Medicaid services for workers with disabilities through **Medicaid Buy-In programs**. To date, a total of $57 million in MIG grants have been awarded to 42 states and the District of Columbia. States receiving funding in 2004 include Alabama, California, Illinois, Indiana, Kansas, Louisiana, Maine, Maryland, Nebraska, Nevada, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, South Carolina, South Dakota, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin, and Washington, D.C.

More specifically, **Medicaid Buy-In** programs allow people with disabilities to keep Medicaid coverage when they become employed by "buying in"—the buy-in helps pay for personal assistants for those who need help with bathing, dressing and shopping, and other improvements to better help individuals with disabilities to remain in the community and hold down jobs. As with CMS' "investment in self-direction," described above, CMS has seen remarkable progress over the course of a very short period. Twenty-eight states have Medicaid Buy-In programs, and four additional states have state plan amendments under review. As of June, 2004, there were approximately 67,000 workers receiving Medicaid benefits under the Buy-In option, *representing more than a nine-fold increase in participation since January 1, 2000.*

Another way CMS is ensuring that *disability does not determine employment status* is through our supports for impaired workers. These workers are individuals who, without medical assistance, would *become* disabled. The **Demonstration to Maintain Independence and Employment** (DMIE) Grant program allows states to provide Medicaid benefits and services to these at-risk impaired workers. An annual appropriation of $42 million was made for fiscal years 2001 to 2004, and $41 million was appropriated for both FY 2005 and FY 2006 for demonstration projects. CMS has worked with Mississippi and the District of Columbia to implement demonstration projects; more states are expected to participate through a solicitation that will be announced within the coming months.

Moving People from Institutions into the Community

The doors must first be opened to ensure independence is even obtainable, but CMS also recognizes that the *pathway* must also be clear once those doors are-- quite literally-- opened. Once individuals depart an institutional setting for an independent life in the community, they may need assistance with certain one-time expenses, such as security deposits and essential household furnishings. Therefore, on May 9, 2002, CMS announced a clarification in policy to allow Medicaid to pay for these expenses. This marked another step in CMS' efforts to support the transition of persons with disabilities from institutions to suitable arrangements in community-based care. A number of states are now paying for such transition costs in aid of moving people from institutions to a community residence. These states are: Connecticut, Indiana, Louisiana, Massachusetts, Minnesota, Nebraska, New Hampshire, New Jersey, Oregon and Wisconsin. Going beyond the policy clarification noted above, CMS has also made grant funds directly available to states in support of these transition/diversion activities. To date, approximately 2,300 individuals have been *transitioned from, or diverted from*, nursing homes into the community with grant assistance from CMS.

Money Follows the Person—
Helpful Clarification to States

On September 17, 2003, a State Medicaid Directors' letter was released to clarify the concept and provide examples of "Money Follows the Person." A follow-up letter was released on August 17, 2004. These letters are designed to be useful tools for states that are looking to take advantage of opportunities to rebalance long-term care systems by providing more community-based alternatives to nursing homes. The letters detail several state initiatives to provide appropriate support services in individuals' own homes or other community settings.