Roadmap for Medicaid Reform

New Options to Support Individuals With Disabilities and Long-Term Care Needs

States can use the DRA as well as other programs, as a strategy to align the Medicaid Program with today's health care environment to:

- **Expand coverage for individuals with disabilities**
- **Increase access to community supports**
- **Promote personal responsibility, independence, and choice**

For more than a decade, States have been asking for the tools to modernize their Medicaid programs. With the enactment of the Deficit Reduction Act of 2005 (DRA) States now have new options to create programs that are more aligned with today's Medicaid populations and the health care environment. Medicaid should keep pace with the people it serves, and nowhere is this more clear than in supporting individuals with disabilities and long-term care needs. About one-third of Medicaid spending is for long-term care (projected to be approximately $100 billion in FY 2007).

The DRA reflects a growing consensus on transforming the long-term supports provided under Medicaid--reforming State programs from being institutionally-based and provider-driven, to "person-centered" and consumer-controlled. It recognizes the role of Medicaid in supporting individuals in their desire to attain and retain independence and self-care in their own homes and communities. It renews the promise of *freedom* for every individual with a disability or long-term illness. The DRA is a long-awaited commitment to independence, choice, and dignity for countless Americans who want to have control of their lives, and gives States many of the tools they need to "rebalance" their long-term support programs.

The 8.4 million individuals with disabilities who are enrolled in Medicaid account for 44 percent of total Medicaid expenditures ($102 billion in 2003) and the 5.1 million low-income elderly in Medicaid account for 24 percent of expenditures ($55.5 billion in 2003). Of the Medicaid funds spent on behalf of individuals with disabilities, 37 percent of Medicaid dollars are for long-term care services. Of the Medicaid funds spent on behalf of aged individuals, 69 percent of Medicaid dollars are for long-term care. Helping individuals remain in their own homes and allowing them to make their own choices of providers has been demonstrated to increase consumer satisfaction that translates into lower utilization of less appropriate (and higher cost) emergency rooms and institutional care. Helping individuals with disabilities return to the workforce has been demonstrated to increase their earnings, while maintaining their access to vital coverage.

Medicaid has absorbed a significant share of the cost of deinstitutionalization, but what are provided are more accurately characterized as social services that are provided under Home and Community-Based Services (HCBS) waiver programs. And even in the cases of HCBS, Medicaid is provider-driven with much of the decision-making in the hands of others, who through "case management" determine what services available, the amount of services to be provided, and from whom the individual will receive those services. Quality services are more likely to be delivered where there is true access and choice.

Nationally, institutional-based care still accounts for 70 percent of long-term care spending in Medicaid. HCBS waiver programs have been an interim solution of expanding choices while creating value. Between 1999 and 2002, the average nursing home payment increased from $19,688 to $22,247, or 13 percent. By comparison, the average cost per participant in a home HCBS waiver increased from $16,083 to $16,437, or 2.2 percent. But the historical focus on a medical model for the provision of HCBS has still often resulted in less efficient and less effective service delivery.

To assist individuals with disabilities and our seniors in need of longer term care services and supports, with the tools added by the DRA, a State can:

1. **Expand coverage for individuals with disabilities**:

    - Allow families with disabled children to purchase Medicaid;
    - Adopt health coverage options for working individuals with disabilities; and
    - Help individuals with disabilities return to the workforce and remain independent.

2. **Increase access to community supports** so that disabled and elderly individuals have true choice of a range of quality options:

    - Offer HCBS without waivers;
    - Apply for grants to "rebalance" their long-term support systems;
    - Apply for Real Choice Systems Change (RCSC) Grants for Community Living; and
    - Apply for demonstration projects to offer home and community-based alternatives to psychiatric residential treatment facilities for children.

3. **Promote personal responsibility, independence and choice** by helping individuals to take control of their long-term support needs, including planning for the future; and to make rational, informed choices about all types of health care needs; such as:

    - Offering a State plan benefit for self-directed personal care services without a waiver; and
    - Opting to participate in the State Long-Term Care Partnership Program.

To expand coverage for individuals with disabilities, a State can:

- **Expand coverage to allow families with disabled children to purchase Medicaid coverage.** Beginning January 1, 2007, States may choose to allow families (with family income up to 300 percent of the Federal poverty level) to buy Medicaid coverage for their disabled children. This flexibility allows States to help working families have access to the critical supports Medicaid provides without further financial strain. States can extend this critical life-line to families struggling to make ends meet by charging a sliding-scale premium based on family income**.**

- **Create new health coverage options for working individuals with disabilities.** States can apply for Ticket to Work and Work Incentives Improvement Act Medicaid

Infrastructure Grants each year through 2011. These grants allow working individuals with disabilities to "buy-in" to Medicaid and receive access to critical personal assistance and other health and employment services.

- **Help individuals with disabilities return to the workforce and remain independent.** States can continue to apply for a "Demonstration to Maintain Independence and Employment". This demonstration, created by section 204 of the Ticket to Work and Work Incentives Improvement Act of 1999 (P.L. 106-170), allows States to provide benefits to workers who have physical or mental impairments. The purpose of the demonstration is to determine whether and how the provision of medical assistance and related services can assist individuals with potentially disabling conditions to remain employed and independent of the income assistance programs: Social Security Disability Income or Supplemental Security Income. Applications will be accepted from States through June 30, 2006.

As States adopt "benchmark plans" for non-disabled populations described in the acute care roadmap document, States are likely to re-examine their State plan and improve acute care benefits for people with disabilities. The new ability to target benefits that more accurately reflects the needs of people with disabilities should result in moving some acute care benefits (i.e., additional therapies, higher limits on prescription drugs, durable medical equipment) from Home and Community-Based Waiver programs into the State plan. It should also create new opportunities for disease management and care management to improve outcomes for individuals with chronic conditions.

To increase access to community supports, States can:

- **Offer home and community-based services without waivers.** Beginning January 1, 2007, States can amend their State plans to offer home and community-based services as a State plan optional benefit. This significant step towards ending the "institutional bias" allows States to offer community-based services to individuals based on their functional need, not on their need for institutional care. This option breaks the eligibility requirement that an individual can receive community services only if he or she needs an institutional level of care. Entry into an institution would be more stringent. This fundamental shift in the program recognizes that not everyone wants or needs institutional care. Individuals will be provided individualized care plans based on an assessment of needs and may be offered the option of self-directing their care. States will be able to establish the number of individuals served under the home and community-based State plan option and thus will have necessary control over the development and growth of their systems so that they can ensure the success of the programs. At the same time, States will be able to tighten the standard for admission to institutions and refine eligibility for home and community-based waiver services without having to request an 1115 demonstration.

- **Apply for grants to "rebalance" their long-term support system.** The Money Follows the Person (MFP) Rebalancing Demonstration supports State efforts to "rebalance" their long-term care support systems by offering $1.75 billion in competitive grants to States

over 5 years. With this critical assistance, States will be able to make targeted reforms in their State to shore up the community-based infrastructure so that individuals have a choice of where they live and receive services. Specifically, the Federal Government will give an MFP-enhanced Federal Medical Assistance Percentage rate for a period of 1 year for each person that the State transitions from an institution to the community. Demonstration grants will be awarded beginning January 1, 2007, through 2011. These grants will also encourage States to adopt a strategic approach to improving quality in both HCBS and nursing homes as the State designs and implements its rebalancing initiative.

- **Apply for Real Choice System Change (RCSC) Grants for Community Living**. This spring, States and other eligible organizations, in partnership with their disability and aging communities, may submit proposals to design and construct systems infrastructure that will result in effective and enduring improvements in community long-term support systems. With this solicitation, CMS invites proposals for grants totaling more than $20 million to address critical elements of successful systems transformation, including improved access to Long Term Care support services, comprehensive quality management, information technology, increased choice and control, and increased access to safe and affordable housing. Since FY 2001, CMS has awarded over 297 grants to all 50 States, the District of Columbia, and 2 territories, totaling approximately $240 million.

- **Apply for demonstration projects to offer home and community-based alternatives to psychiatric residential treatment facilities for children.** States can keep families together by expanding the availability of HCBS to children under age 21 with serious emotional disturbances. These children would otherwise be removed from their families and placed in a psychiatric residential treatment facility in order to receive needed services. In the past, States were unable to develop home and community-based waiver programs as an alternative to this institutional care because the law had only permitted such programs as an alternative to care in a hospital, nursing facility or intermediate care facility, for the mentally retarded. The Secretary is now authorized to conduct five-year demonstration projects in up to 10 States during the period from FY 2007 through FY 2011. The proposal appropriates $218 million for the project period, and, of that amount, $1 million is made available for required interim and final evaluations and reports.

To promote personal responsibility, independence and choice, States can:

- **Offer a State plan benefit for self-directed personal care services without a waiver.** Individual-controlled budgets provide for the transparency and informed choice believed to be vital to improve quality and value. Self-directed personal care services are currently provided through HCBS and section 1115 demonstration waiver programs. Indeed, nearly half the States now offer self-direction in some capacity, although self-direction is still available to only limited numbers of people. With this new option, self-directed personal care services, including self-directed personal care services provided by family members, can be provided under the State plan. States will also be able to provide items that increase independence or substitute for human assistance.

Thus, States become partners with individuals and their families, friends, and health care professionals in creating individualized plans and budgets that will give individuals control of their lives. The person's preferences, choices, and abilities drive how they receive services. In addition, States can incorporate participant direction into an existing or a new home and community-based waiver program. The new application walks States through a step-by-step process that enables the use of program design strategies that afford participants increased independence, choice, and responsibility for their services.

While States may be concerned that self-direction may be subject to fraud or replace parental care with paid care, experiences to date and program evaluations dispel both concerns. The evidence shows that needs assessment tools and use of fiscal agents assure accountability and cost effectiveness.

- **Opt to participate in the State Long-term Care Partnership Program**. This program was established to help individuals take more responsibility in planning for and financing their future long-term care needs by purchasing long-term care insurance. The program allows an individual who purchased a qualified policy, but who eventually uses all its benefits, to apply for Medicaid without having to spend most of his or her assets first. Specifically, an individual will be able to qualify for Medicaid while retaining assets in the amount of insurance benefit payments made on their behalf under their insurance policy. These newly protected assets will also be exempted from Medicaid estate recovery provisions.

Conclusion

In adopting the new options available under the DRA, States will help families and individuals attain or retain capability for independence and self-care and rebalance their long-term support programs to make their Medicaid programs more sustainable.