

medicaid and the uninsured

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Medicaid Long-Term Services Reforms in the Deficit Reduction Act

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EXECUTIVE SUMMARY

The Deficit Reduction Act of 2005 (DRA) was signed by the President in February 2006.* Long-term services and supports, sometimes called long-term care, provide assistance with everyday activities, such as assistance with dressing, bathing, using the bathroom, preparing meals, taking medication, managing a home, and managing money. The DRA makes several major changes to long-term services policies in Medicaid. Key changes include:

- **Asset Transfers:** Requires states to lengthen the look-back period for asset transfers to establish Medicaid's eligibility for nursing home coverage from 3 to 5 years and changes the start of the penalty from the date of the transfer to the date of Medicaid eligibility; requires annuities to be disclosed and states to be named a beneficiary for cost of Medicaid assistance; requires state to use the income first rule; and excludes coverage for individuals with home equity in excess of \$500,000 (or up to \$750,000 at state option), with an exception when a spouse or child with a disability is residing in the home.
- **Long-Term Care Partnership Programs:** Lifts the moratorium on states expanding new partnership programs to increase the role of private long-term care insurance in financing long-term services; requires programs to adopt National Association of Insurance Commissioners (NAIC) model regulations; and requires the Secretary to develop standards for making policies portable across states.
- **Family Opportunity Act:** Creates a new option for states to extend Medicaid "buy-in" coverage to children with disabilities with family income up to 300% of poverty; coverage is phased in starting in 2007 for children up to age 6 and rising to age 19 by 2009; states are permitted to charge income-related premiums, and parents must participate in employer-sponsored insurance if the employer covers at least 50% of the premium.

*The President signed the bill, the Deficit Reduction Act of 2005 (S. 1932), on February 8, 2006, and it has since been designated Public Law 109-171. Subsequently, it was learned that both the Senate and the House of Representatives did not pass the bill in identical form. While the White House and Congressional leadership have stated that they believe this is a minor technical issue and that the bill is a law, others have asserted that, based on the Bicameralism Clause of the U.S. Constitution, the Deficit Reduction Act was not lawfully enacted. The Congressional Budget Office has estimated that differences in the bill affect \$2 billion of federal spending. Resolution of this issue may require the involvement of the federal courts. For purposes of this analysis, the author has reviewed the signed bill as though it is a federal law.

- **Money Follows the Person Demonstration:** Authorizes the Secretary to grant competitive awards to states to increase the use of community versus institutional services; provides for an enhanced federal medical assistance percentage (FMAP) for 12 months for each person transitioned from an institution to the community during the demonstration period; eligible participants must have resided in an institution for a period from 6 months to 2 years, as determined by the state; and states must continue to provide community services after the demonstration period for as long as the individual remains on Medicaid and in need of community services.
- **State Option to Provide HCBS Services:** Creates a new state option for states to provide all HCBS waiver services without needing to get a waiver to seniors and people with disabilities up to 150% of poverty; there is no requirement that eligible beneficiaries require an institutional level of care; requires states to establish more stringent eligibility criteria for institutional services; and permits states to cap enrollment, maintain waiting lists, and offer the option without providing services statewide.
- **Cash and Counseling Option:** Permits states to allow for self-direction of personal assistance services without needing to get a waiver; includes consumer protections consistent with the cash and counseling demonstration; prohibits individuals from participating in self-direction under the option if they live in a home or property owned or controlled by a services provider; and does not require comparability or statewideness.

Policy Implications

Through the DRA, the Congress has made significant changes to the rules that states must follow in extending eligibility for Medicaid, it has altered the role of Medicaid vis à vis private long-term care insurance, and it has created new incentives and opportunities for states to re-focus their Medicaid long-term services delivery systems away from nursing homes and toward a greater community orientation. In all of these areas, the policy changes represent an effort to ensure that the federal and state financing obligation is either limited—or at least, directed to the most cost-effective and desirable services for seniors and people with disabilities. The ultimate impact of these changes remains to be determined by how states and other stakeholders respond. Although the changes are considerable, they reflect somewhat piecemeal reforms aimed at promoting community-based care and limiting access to institutional care.

In many cases, these changes reflect a long-sought policy direction by beneficiaries. Other changes reflect an effort to limit the public role in financing long-term services for low-income Americans. As beneficiaries, states, and providers continue to advance their own policy agendas, the DRA is an indication of emerging federal policy in this area.

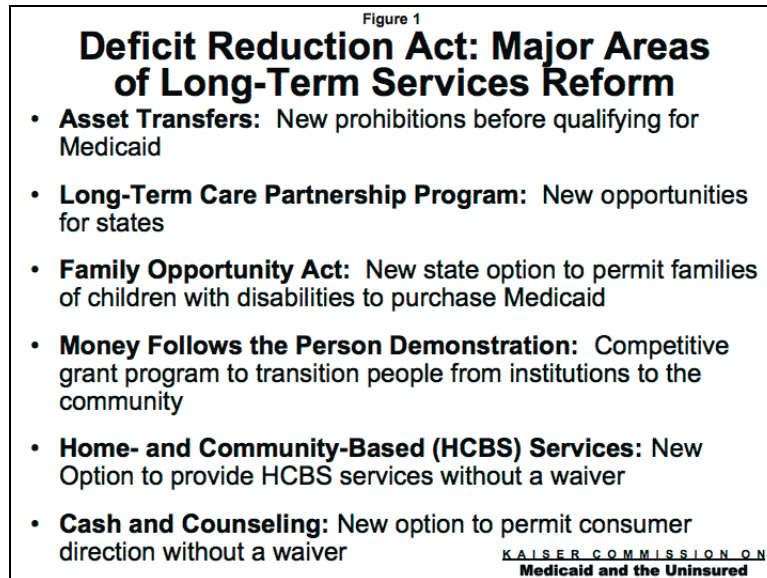
INTRODUCTION

The Deficit Reduction Act of 2005 (DRA) was signed by the President in February 2006.[†] The Congressional Budget Office (CBO) estimates that the Medicaid provisions of the DRA will reduce federal spending by \$6.9 billion over the next five years, with new spending for the State Children’s Health Insurance Program (SCHIP) and Hurricane Katrina health care relief leading to a net Medicaid spending reduction of \$4.7 billion.¹ The Medicaid provisions of the DRA make significant changes in a number of areas, including prescription drug payment policies, premium and cost-sharing rules, flexibility in offering alternative benefits packages, long-term services reforms, and citizenship documentation requirements.

Long-term services and supports, sometimes called long-term care, provide assistance with everyday activities, such as assistance with dressing, bathing, using the bathroom, preparing meals, taking medication, managing a home, and managing money. Providing such assistance to maximize independence was an original purpose of Medicaid, but the emphasis on providing services that permit individuals to live in their own homes represents a focus that was not present when Medicaid was established forty years ago.

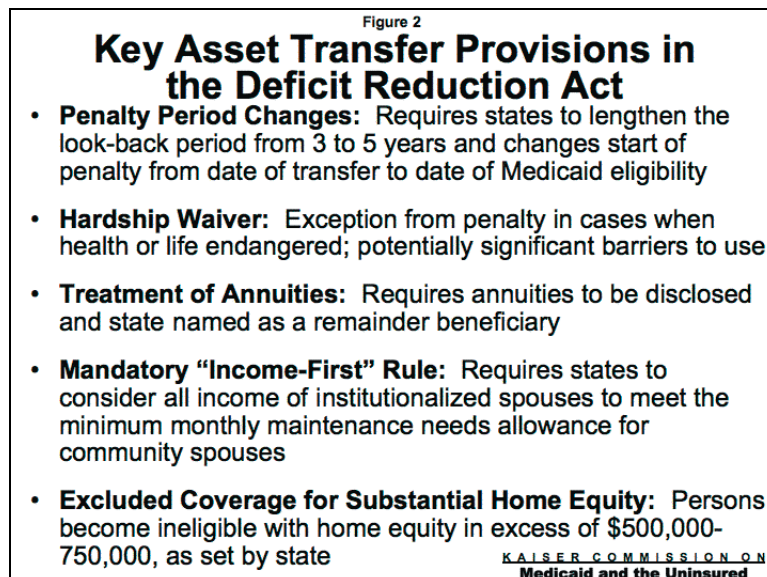
The DRA makes many extensive changes to long-term services policies in Medicaid. **(Figure 1)**. This issue brief summarizes major areas of reform. It does not cover every detail, but instead seeks to highlight key issues of interest to policy makers. In some cases, such as changes in asset transfer rules, the effect of the DRA could be reduced eligibility for Medicaid. In others, including the State Long-Term Care Partnership Program and the Family Opportunity Act, the DRA might lead to more individuals qualifying for Medicaid—and receiving access to Medicaid long-term services and supports. Other provisions of the DRA give states expanded flexibility in delivering long-term services and may lead to expanded access to community-based long-term services.

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Asset Transfers²

The asset transfer changes in the DRA are some of the most controversial (**Figure 2**). They were supported by states, but opposed by beneficiary advocates, as well as the National Association of Elder Law Attorneys, the professional association for attorneys who advise individuals and families on issues related to financial eligibility for Medicaid long-term services. These provisions are effective on the date of enactment, and do not apply to asset transfers made before enactment of the DRA.



When an individual transfers an asset at less than fair market value (such as by giving cash gifts to children or other family members, or transferring ownership of one’s home), they become subject to a penalty that delays the date upon which they qualify for

Medicaid. The DRA makes two substantive changes in how the penalty is assessed. First, states were previously required to have a three-year look-back period for prohibited transfers and the DRA changes this to five years. Second, the start of the penalty is changed from the date that an asset transfer is made to the date that an individual otherwise would have become eligible for Medicaid. The DRA also requires states to eliminate rounding down when determining the penalty period and it allows them to view many transfers in different months as one, large transfer, on which to base their calculations. The DRA establishes a hardship waiver that permits states to make an exception to the penalty in cases where it would threaten the health or life of the individual or when the application of the penalty would deprive the individual of food, clothing, shelter and other necessities of life.

Annuities are financial instruments where a sum of money is transferred to the control of a financial institution (often at retirement) that agrees to pay out a predetermined amount of money on a regular (*i.e. monthly*) basis for the life of the owner of the annuity or for a pre-determined period, such as five to ten years. Prior to the DRA, annuities were treated as exempt assets, and not subject to a penalty. The DRA changes the treatment of annuities so that they are treated as prohibited asset transfers subject to a penalty, unless Medicaid applicants disclose the existence of annuities and name the state as the primary beneficiary of the remainder (at the death of the annuitant) for at least the value of Medicaid assistance provided. The DRA also requires individuals who paid an entrance fee to a continuing care retirement community or a life care community to spend their entrance fee on their care before qualifying for Medicaid.

The DRA requires states to use the “income-first” rule when determining the monthly income maintenance needs allowance for the community spouse. More than half of the states already used this rule in which states must consider all income available to an institutional spouse when calculating the income of the community spouse. This change may have the effect of lowering the amount of income that can be retained by the community spouse. The DRA also requires states to make individuals with substantial home equity ineligible for Medicaid nursing home services or other long-term services. The home equity cutoff is \$500,000, but states are permitted to raise this to \$750,000. There is an exception to this policy if there is a spouse or child with a disability residing in the home.

Policy Implications: As Medicaid costs grow, there is a growing interest by many policy makers, including some Members of Congress, in restricting Medicaid eligibility to the “truly needy”. Tightening the eligibility standards for persons who transfer assets is a key issue for many because they believe that existing standards permit upper income individuals who have the resources to pay for their own long-term services to qualify for Medicaid. Some contend that individuals may not plan properly for their future needs because they know that Medicaid is available as a safety net. The research literature has not substantiated many of the claims made about upper-income people divesting large amounts of assets to qualify for Medicaid.³

Some of the asset transfer policy changes are areas where broad consensus exists. This includes the provision that allows states to view many transfers in different months as one, large transfer. Other policies, however, have been supported by some states, but have been strongly resisted by beneficiary advocates. In particular, the change in the start of the penalty period is viewed by some as a measure that could unfairly penalize individuals who spend their own funds for a variety of socially beneficial reasons (whether it is assisting grandchildren with college expenses, tithing, or making charitable contributions). Even transfers made several years before an individual needs long-term services and not done for the purpose of qualifying for Medicaid can now subject individuals to a penalty.

Critics of these changes maintain that the hardship waivers will not provide meaningful protection to individuals because the evaluation of hardship is subjective and existing hardship waivers are almost never used.⁴ Another significant area of concern relates to the requirement that states use the income-first rule. This policy could lead to greater financial insecurity for some couples, but could also increase Medicaid costs if it leads both spouses to end up as Medicaid nursing home residents.

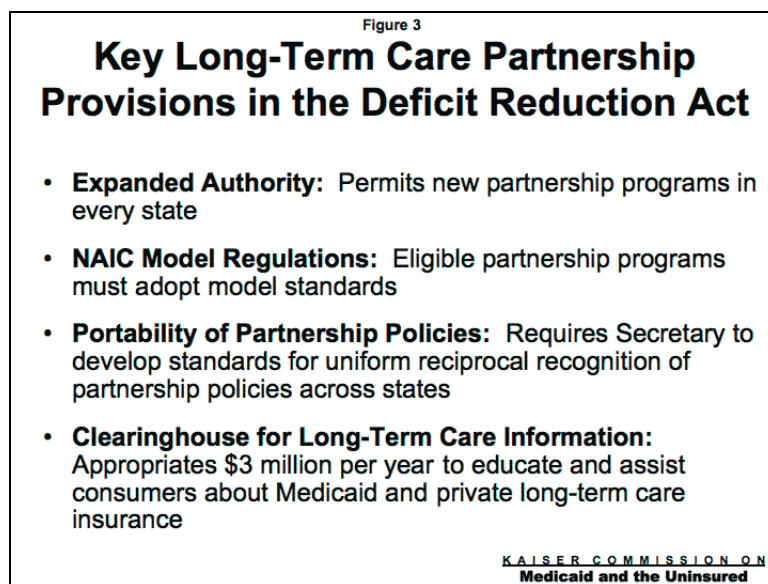
The DRA also makes a fundamental change in the treatment of a beneficiary's home. Prior to the DRA, Medicaid disregarded the full value of any primary residence. The DRA makes persons with substantial home equity ineligible for Medicaid long-term services, with an exception from this policy if there is a spouse or child with a disability residing in the home. Individuals become ineligible for Medicaid if they have home equity of more than \$500,000, and states can increase this home equity disregard up to \$750,000. This state flexibility appears to reflect a recognition that home valuations vary dramatically across the country. At the same time, this flexibility may not be sufficient to fully address differences in housing costs. In some parts of the country, \$500,000 purchases a sizeable luxury home, whereas in some communities, even \$750,000 may be insufficient to purchase even a very modest home. This policy runs counter to other efforts in the DRA to promote the provisioning of community services, as it makes single individuals (with no spouse or child with a disability in the home) ineligible for community services. Further, it could make it more difficult to transition individuals out of nursing homes and other institutions if this requirement forces individuals to divest themselves of their community housing.

CBO estimates that the asset transfer policies will reduce Medicaid spending by \$2.4 billion over the 2006-2010 period and by \$6.3 billion over the 2006-2015 period. Savings result primarily from changes to the asset transfer penalty policies and by making individuals with substantial home equity ineligible for Medicaid long-term services.⁵

Long-Term Care Partnership Programs⁶

For many years, a variety of policy makers have sought to increase the role of private long-term care insurance in financing long-term services in the United States. As part of

a broader policy debate over how to establish a dynamic insurance market with widespread participation, there has been a debate over the role of Medicaid as a disincentive for Americans to purchase long-term care insurance and as a tool for encouraging the purchasing of insurance. In early the 1990s, Congress established the Long-Term Care Partnership program. Four states (California, Connecticut, Indiana, and New York) established programs. In response to concerns that promoting private long-term care insurance was beyond the mission of the Medicaid program and that the insurance products offered were of limited value, Congress established a moratorium on the establishment of new programs in 1993.⁷ The DRA lifts the moratorium and permits all states to establish partnership programs (**Figure 3**).



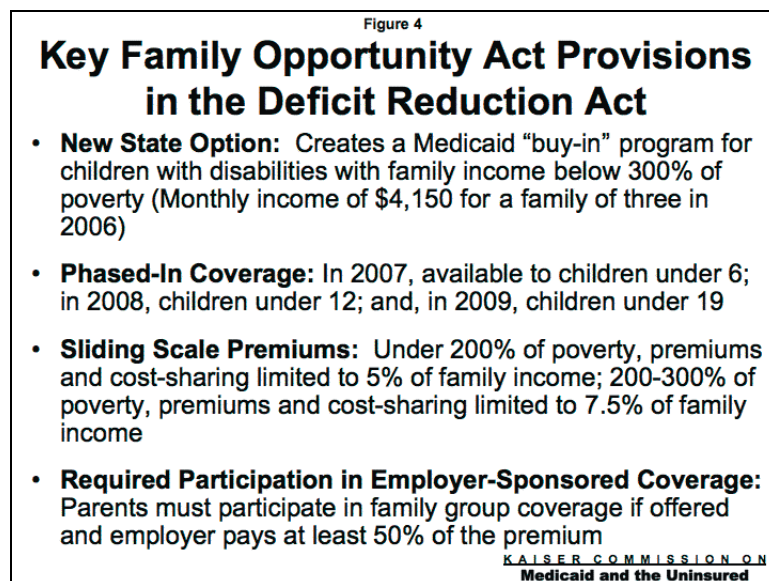
Partnership programs are insurance policies in which Medicaid disregards an amount of assets or resources when determining eligibility for Medicaid equal to the insurance benefit payable under the insurance policy. Incentives are built in to encourage individuals to purchase insurance at a young age—to expand the risk pool. Policies purchased before an individual turns 61 must provide for compound annual inflation protection. Policies first purchased by individuals between ages 61-76 must provide some level of inflation protection, and policies first purchased after age 76 may, but are not required to, provide some level of inflation protection. The DRA requires state partnership programs to comply with model guidelines established by the National Association of Insurance Commissioners (NAIC). It also requires the Secretary to consult with relevant stakeholders to develop standards for uniform reciprocal recognition among states with partnership programs. The DRA also instructs the Secretary to establish a clearinghouse for long-term care information.

Policy Implications: CBO estimates that the partnership programs will increase Medicaid spending by \$26 million over the 2006-2010 period and \$86 million over the 2006-2015 period.⁸ In the past, concerns have been raised over the quality of insurance coverage that individuals can purchase under the partnership programs. Congress has taken steps to standardize and improve coverage provided under

partnership insurance policies by requiring states to ensure that policies follow NAIC model regulations. The DRA's requirement that partnership policies provide portability is seen as an important improvement, and may make this coverage more attractive in the future. Nonetheless, the DRA provisions may not address some of the major shortcomings of existing partnership programs: most seniors have very low-incomes, partnership policies are generally not affordable to low- and moderate income individuals; and partnership policies are not available to people with disabilities and others who already require long-term services and supports.⁹

Family Opportunity Act¹⁰

The inclusion of the Family Opportunity Act (FOA) in the DRA was preceded by more than six years of concerted bipartisan efforts in both houses of Congress to enact these provisions. It creates a new state option to permit states to offer Medicaid buy-in coverage to children with disabilities in families with income below 300% of the federal poverty level (**Figure 4**). States are permitted to cover eligible children with family income above 300% of poverty, but with state-only funds. Coverage for the option is phased in over three years, starting in 2007. States are permitted to charge income-related premiums, but if they do so, they must apply them in a uniform manner on a sliding scale basis. Further, total premium and cost-sharing payments are limited to 5% of family income for children with family income below 200% of the poverty level and 7.5% of family income for children with family income between 200-300% of poverty. The DRA requires parents to purchase employer-sponsored family coverage, when offered, if the employer pays at least 50% of the premium cost. In such a case, any Medicaid premiums must be reduced by an amount that reasonably reflects the employer-sponsored insurance premium attributable to the child with a disability. States are also permitted to pay any portion of the employer-sponsored premium for family coverage.



Policy Implications: The FOA option adds to the tools available to states to extend Medicaid coverage to children with disabilities in order to provide community-based long-term services. Since 1982, the TEFRA (or Katie Beckett) option has permitted states to waive the requirement to consider parental income when assessing eligibility for Medicaid for children with disabilities.¹¹ This option has been used by many states to provide community services to children with disabilities, but it is only available to children who require a hospital or nursing facility level of care, for whom home care is medically or otherwise appropriate, and when community-based services would not exceed the cost of appropriate institutional care. States have also used “less restrictive income and resource” rules (as permitted under Section 1902(r)(2) of the Social Security Act) when determining eligibility for Home- and Community-Based Services (HCBS) waiver programs (also called 1915(c) waivers) to provide community-based services to children with disabilities. But, these programs also require individuals to need an institutional level of care and they require that spending on community services is budget neutral—or cost no more than institutional services. A major advantage of the FOA is that it lets states extend Medicaid coverage to children who meet the Social Security standard for disability, but who do not need an institutional level of care and there is no budget neutrality requirement.

The CBO estimates that 115,000 children with disabilities will gain Medicaid coverage by 2015 as a result of these provisions. For 55,000 of these children, CBO estimates that Medicaid would supplement employer-sponsored health insurance coverage and another 5,000 of these children would otherwise be enrolled in the SCHIP program, but will gain access to Medicaid as a result of these provisions. It is estimated that these provisions will increase Medicaid spending by \$1.4 billion over the 2006-2010 period and \$6.4 billion over the 2006-2015 period. Further, CBO estimates that about two-thirds of the states will eventually provide Medicaid coverage under these provisions.^{12,13}

Money Follows the Person Demonstration¹⁴

The Money Follows the Person Demonstration was included in the DRA after being proposed by the President in his annual federal budget proposal for several years. This demonstration is a key part of the President’s *New Freedom Initiative*, and was strongly backed by many advocates for people with disabilities. Various states, such as Texas, Utah and Vermont, have also enacted their own *Money Follows the Person* programs with similar goals, but without enhanced federal payments.¹⁵

The demonstration program authorizes the Secretary of Health and Human Services to award competitive grants to increase the use of home- and community-based rather than institutional long-term services; to eliminate barriers that prevent or restrict the flexible use of Medicaid funds to enable beneficiaries to receive services in the setting of their choice; and to assure continued access to community services to individuals who have transitioned out of an institution (**Figure 5**). The demonstration program creates an incentive for states to “rebalance” their long-term services programs by

providing for a grant program lasting at least two consecutive years. During a state's grant period, they will receive an enhanced match for home- and community-based services for each eligible individual that transitions from an institution to the community for a 12-month period, from the date of discharge from an inpatient facility. Eligible individuals must be residents of an institution and must meet a length of residency requirement that is set by the state, but that can range from six months to two years. Qualified institutions include hospitals, nursing homes, and intermediate care facilities for persons with mental retardation (ICF-MRs), and to the extent that Medicaid state plan services are available, to institutions for mental disease (IMDs).

Figure 5

Key Money Follows the Person Provisions in the Deficit Reduction Act

- **Competitive Demonstrations:** Secretary awards grants to increase use of Medicaid community-based services over the use of institutional services
- **Incentive for Community Services:** Provides for enhanced FMAP for an individual's costs for 12 months from date of institutional discharge; after 12 months, state continues services at regular FMAP
- **Enhanced Federal Payments (FMAP):** Federal share of community long-term services is increased to 75-90%, depending on state
- **Eligible Participants:** Medicaid beneficiaries in institutions for residency period set by state (from 6 months to 2 years)
- **Funding:** \$1.8 billion appropriated over the 2007-2011 period

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The enhanced federal medical assistance percentage (FMAP) is based on a state's existing FMAP, but will cover from 75-90% of total expenditure's for an individual's community-based long-term services. The formula for the enhanced FMAP is the state's existing FMAP plus one-half of the difference between 100% and the state's FMAP. For example, in a state with an FMAP of 60%, the enhanced FMAP is 80%:

$$\text{Enhanced FMAP} = \text{Current FMAP} + \frac{1}{2} [100 - \text{current FMAP}]$$

Recipient states must maintain access to community services after the demonstration period for as long as participating beneficiaries need the services and remain eligible for Medicaid. States are permitted to provide for self-direction of services (by the individual or their authorized representative). Self-direction permits individuals who require personal assistance to actively direct the provision of services, and this includes recruiting, supervising, hiring and firing personal assistance providers. Under the model of self-direction contemplated under the DRA, individuals receive an individual budget for a set of services that are "cashed out". If a state elects to permit self-direction as part of their demonstration program, they must ensure that participation in self-direction is voluntary and that the state complies with basic consumer protection standards, such as conducting an assessment and person- or family-centered planning process. Further, there must be a written service plan developed with the individual (or their

authorized representative) that specifies the services which will be subject to self direction, the method and by whom services providers will be selected, managed, and dismissed, and the role of family members and other persons whose participation is sought by the individual. The budget process for services to be self directed must describe the method for calculating the dollar values of the budget and the process for making adjustments to the budget to reflect changes in individual assessments and service plans; and it must provide for a procedure for evaluating expenditures under such budgets. Participating states must implement a plan for assuring quality and to improve the quality of community services.

In awarding grants under the demonstration, the Secretary must seek an appropriate national balance in the numbers of eligible individuals within different target groups who are assisted to transition to the community under the demonstration. Priority must be given to state applications that propose to transition individuals from multiple target groups and that provide for an opportunity to self-direct services. A total of \$1.8 billion is appropriated for the demonstrations, with \$250 million available for grants in 2007, with this level of funding rising to \$450 million in 2011.

Policy Implications: In 2004, 64% of Medicaid long-term services spending—or \$57.6 billion—was for institutional services.¹⁶ The goal of the Money Follows the Person demonstration is to help shift more of those funds to the provisioning of community services. Spending on the demonstrations, however, represents less than one-half of one-percent of long-term services spending. Nevertheless, the demonstration is part of a broader trend—supported across the political spectrum—to take concrete steps to mitigate the institutional bias in Medicaid which exists because there is an entitlement to institutional services, whereas community services remain optional for states, and often in short supply. Further, this type of initiative compliments other efforts, such as nursing home diversion programs (which seek to avoid placement in a nursing home in the first place) by seeking to demonstrate that it is possible to transition people out of institutions. Successfully transitioning people out of institutions is believed to be significantly more difficult than providing community services to individuals already living in the community. This is because most people who have been institutionalized have given up a home (or other community living arrangement) and Medicaid funds are generally not available for room and board and other expenses that must be incurred to establish a community residence. In this context, the Money Follows the Person demonstration provides an innovative incentive for states to reallocate long-term services funding to community options—and a temporary period of enhanced federal matching funding will free up state Medicaid funds that potentially could be re-applied to assisting individuals in paying for one-time transition expenses (such as rental security deposits).

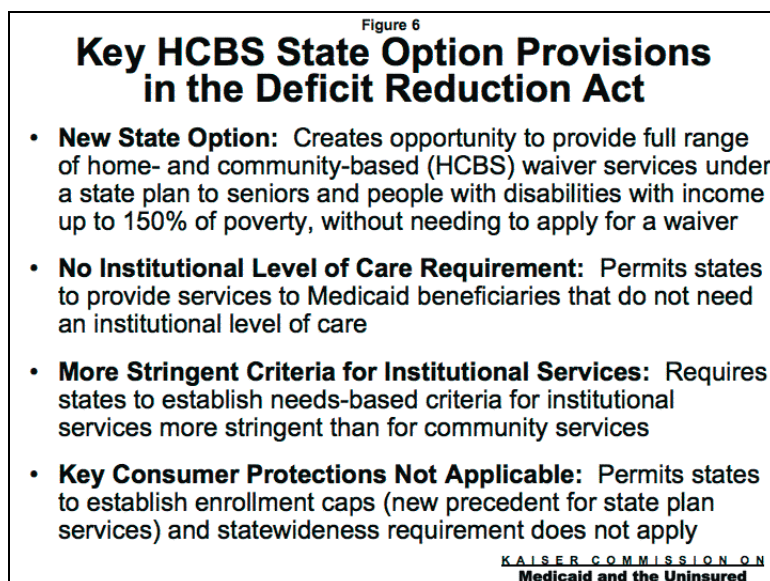
Even though \$1.8 billion is appropriated for the initial five years of the demonstration, the CBO estimates that offsetting savings resulting from reduced institutional spending will lead to increased federal costs of only \$340 million, and \$2.0 billion over the 2007-2015 period.¹⁷ These estimates are based on the assumption that over a three-year period about 100,000 people will leave institutions and receive services through the

program. CBO estimates that even without the program, 25,000 of these individuals would leave institutions and receive community-based long-term services. Further, CBO projects that one-half of participants in the demonstration program will continue to receive Medicaid community-based services for at least a year after the twelve month demonstration period.¹⁸

State Option to Provide HCBS Services¹⁹

The DRA creates a new opportunity for states, starting in January 2007, to provide a comprehensive package of community-based services under their Medicaid state plans that previously could only be provided through the home- and community-based services (HCBS) waiver program.²⁰ For many years, states have advocated for the ability to provide HCBS services without needing to go through the waiver process.

The DRA amends section 1915 of the Social Security Act to permit states to provide the full range of HCBS waiver services to seniors and people with disabilities with income up to 150% of the poverty level as state plan (*i.e. non-waiver*) services (**Figure 6**). Unlike the waiver program, there is no budget neutrality requirement, in which states must demonstrate to federal officials that the provision of community-based waiver services will not increase federal costs over costs that would be incurred if states only provided institutional services. Further, this option (*as with the personal care option*) expands the population of Medicaid beneficiaries eligible for community services by permitting states to use the option to serve persons who do not require an institutional level of care.



The DRA sets a new precedent in Medicaid law by permitting states that take up this option to establish enrollment caps and maintain waiting lists, and provide services under this option only in certain parts of a state. Prior to the DRA, states were required to provide services under any option to all Medicaid beneficiaries for whom they were

medically necessary. Previously, states could establish enrollment caps and limit statewideness only after going through the waiver application process, which involves a federal review of the reasonableness of a state's proposal. Additionally, the DRA provides for "adjustment authority" which permits a state to adjust its eligibility criteria for community services under the option in the event that actual enrollment exceeds projected enrollment, as long as they ensure that individuals participating in the option are able to receive at least twelve months of community services (beginning on the date that they started receiving community services) and eligibility for institutional services is no more restrictive than it was before the state took up the option.

Prior to the DRA, functional eligibility criteria for community services was required to be at least as stringent as the eligibility criteria for institutional services. This option changes the incentives for states by not only permitting less restrictive eligibility criteria for community services, but by requiring it. The DRA requires states that take up this option to establish less stringent needs-based eligibility criteria for community services than for institutional services. For persons receiving institutional services or HCBS waiver services on the date that a state submits a state plan amendment to take up this option, the DRA protects their continued eligibility for institutional or waiver services even if they no longer meet new more stringent eligibility criteria until such time that they are discharged from the institution or waiver program or no longer qualify for Medicaid.

States are permitted to provide for self-direction of services (by the individual or their authorized representative), with similar requirements as under the Money Follows the Person demonstration.

Policy Implications: Key elements of this new state option were taken from Title II of the Improving Long-Term Care Choices Act of 2005 (S. 1602), legislation that was introduced in the Senate in July 2005 by Senators Grassley, Bayh, and Clinton. This legislation was strongly supported by advocates for people with disabilities. The state option that was established by the DRA, however, differs in significant ways from S. 1602. In particular, S. 1602 would not have permitted enrollment caps and waiting lists. While states supported this new option with enrollment caps, the disability community opposed it.²¹

Since the landmark *Olmstead* Supreme Court decision in 1999, there has been a belief that states must take greater steps to eliminate waiting lists in HCBS waiver programs. To the contrary, the size of waiting lists has actually grown since the *Olmstead* decision. In recent years, the size of Medicaid waiver waiting lists has grown from 156,000 in 2002 to 206,000 in 2004.²² It is unclear what impact this new option will have on the size of state waiting lists, and whether states will use the option to expand access to community services, whether the ability to maintain waiting lists under this option will lead to more people on Medicaid waiting lists—or both.

Concerns also have been raised that the new capacity to cap enrollment may effectively weaken the security of existing optional coverage. For example, an estimated 722,000 Medicaid beneficiaries receive services under the personal care option (currently

offered in 30 states plus DC) and an unknown, but significant number of individuals receives services under the rehabilitation services option (currently offered in 46 states plus DC).²³ These are two of the primary state plan options used by states to provide community services. When a state elects these options, individual Medicaid beneficiaries gain a right to receive these services if they need them. Now, states could shift the coverage of personal care or rehabilitation services from existing state plan options to the new HCBS option. Either immediately, or at some future date when a state faced a fiscal crisis, it could limit access to the service in a way that is not currently permitted under the personal care and rehabilitation services options.

Previously, Medicaid beneficiaries have successfully challenged in federal court the reasonableness of a state's eligibility rules for institutional services when changes were made solely to achieve a predetermined level of financial savings.²⁴ Some stakeholders have raised concerns that the requirement under this option for more stringent eligibility for institutional care will be used to justify equally arbitrary changes in the eligibility criteria for institutional services, instead of relaxing the criteria for community services. Indeed, the DRA appears to anticipate this outcome by providing some protections to individuals currently receiving services in institutions and waiver programs from being made ineligible under a new, more stringent eligibility standard.

Another uncertainty related to the option relates to the usefulness of the adjustment authority. Under S. 1602, states that sought to restrict eligibility for community services under the option could "grandfather" coverage for persons already receiving services under the option. This was envisioned as providing states with an alternative to waiting lists for managing the financial risk associated with extending community services in an environment where the level of need cannot be clearly determined. Since the HCBS option, as enacted, only permits services to continue until an individual has received twelve months of community services—instead of permitting states to continue covering people already receiving services indefinitely while limiting access to newcomers, it is unclear whether this authority will serve as a useful tool for states.

Notwithstanding all of these questions, the ultimate impact of this new option on expanding access to community services remains to be seen. The CBO projects that by 2015, states with about one quarter of Medicaid enrollment will use the option to provide community services to about 120,000 people. The option is projected to increase federal costs by \$766 million over the 2006-2010 period and \$2.6 billion over the 2006-2015 period.^{25,26}

Cash and Counseling Option²⁷

In the 1990s, the Department of Health and Human Services, in partnership with the Robert Wood Johnson Foundation, established the Cash and Counseling Demonstration program, under the section 1115 waiver authority, to test the use of individual budgets in which specific services were "cashed out" and individuals were given the ability to purchase and manage personal assistance and other long-term services. Arkansas, Florida, and New Jersey conducted Cash and Counseling

demonstration programs. In 2002, attempting to build on the perceived success of the cash and counseling model, the Bush Administration launched the Independence Plus initiative to encourage all states to provide opportunities for self-direction. This program permits states to develop self-direction programs under the sections 1115 and 1915(c) waiver authorities.²⁸

The DRA establishes a new state option to permit states to allow for self-direction of services, without needing to seek federal waiver approval (**Figure 7**). The new option permits states to use the “cash and counseling” model of providing participating beneficiaries with an individual budget to purchase an array of services that are part of a written plan of care. Under this option, states are permitted to pay for all or part of self-directed personal assistance services to persons who otherwise qualify for personal care services or HCBS waiver services. Safeguards must be included to protect the health and welfare of participants and to ensure financial accountability of funds provided through the option. Individuals are not eligible to participate in the self-direction program if they live in a “home or property that is owned, operated, or controlled by a provider of services, not related by blood or marriage”.

Figure 7

Key Cash and Counseling Provisions in the Deficit Reduction Act

- **New State Option:** Creates opportunity for states to provide for self-direction of services (using the Cash and Counseling individual budget model) without needing to request a waiver
- **Consumer Protections:** Secretary must assure that state proposals include basic consumer protections (similar to Cash and Counseling/Independence Plus)
- **Discriminatory Provision:** Self-directed services may not be provided under this subsection to individuals who reside in a home or property that is owned, operated, or controlled by a provider of services, not related by blood or marriage
- **Stateness and Comparability Not Required**

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Services eligible for self-direction under this option are personal care and related services or home- and community-based waiver services. The option permits states to elect to use any capable individuals as paid providers of services, including legally responsible relatives (*i.e. parents of children with disabilities or spouses*). States can also permit individuals to use their individual budget to “acquire items that increase independence or substitute (such as a microwave oven or an accessibility ramp) for human assistance, to the extent that expenditures would otherwise be made for the human assistance”. States can provide for self-direction under this option without needing to comply with Medicaid’s stateness requirement, and states can limit access to the self-direction program to certain populations (*i.e. comparability is not required*).

Policy Implications: For many years, people with disabilities have advocated for greater ability to control the delivery of their long-term services. In particular, individuals have sought the ability to recruit, supervise, and hire and fire providers of personal assistance services. This new option adds to the tools available to states to provide for self-direction. In the past, beneficiary advocates, while supporting efforts to expand access to self-direction, have raised concerns that the methods that states use to determine the size of the individual budget may not adequately protect individuals, or may fail to respond in a timely manner if an individual's need for services increases. The budget adequacy requirements under this option do not appear to expand on previous requirements on states under the Cash and Counseling or Independence Plus waiver programs.

The Cash and Counseling demonstration tested the applicability of individual budgeting for the delivery of personal assistance services, yet the Independence Plus initiative broadened the scope of services eligible for self-direction to any waiver or state plan service provided by the state. Some beneficiary advocates have raised concern that some services (such as medical services, prescription drugs, or durable medical equipment) may not be appropriate for individual budgeting because of the unpredictable nature of the need for services, the level of financial risk involved, and because individuals are not able to leverage the market power of Medicaid programs to engage in bulk purchasing or negotiate favorable payment rates. The need for personal assistance, on the other hand, is often more predictable and individuals can sometimes leverage their own personal networks to recruit personal assistance providers. Congress limits the use of self-direction under the option to personal care and HCBS waiver services, thus aligning the scope of the option more closely to the Cash and Counseling demonstrations.

The language in this option that restricts participation in self-direction on the basis of ownership or control of an individual's residence has significant implications for certain populations, including many persons with mental retardation and developmental disabilities and individuals with mental illness who may be ineligible to participate in the self-direction program because their house is controlled by a services provider.

The CBO estimates that over the next ten years, 60,000 Medicaid beneficiaries would self-direct services under this option, 25% of whom would not otherwise access Medicaid long-term services. The estimated ten-year cost of this option is \$360 million.²⁹

Conclusion

Through the DRA, the Congress has made significant changes to the rules that states must follow in extending eligibility for Medicaid, altered the role of Medicaid vis à vis private long-term care insurance, and created new incentives and opportunities for states to re-focus their Medicaid long-term services delivery systems away from nursing homes and toward a greater community orientation. In all of these areas, the policy changes represent an effort to ensure that the federal and state financing obligation is either limited—or at least, directed to the most cost-effective and desirable services for seniors and people with disabilities. The ultimate impact of these changes remains to be determined by how states and other stakeholders respond. Although the changes are considerable, they reflect somewhat piecemeal reforms aimed at promoting community-based care and limiting access to institutional care.

In many cases, these changes reflect a long-sought policy direction by beneficiaries. Other changes reflect an effort to limit the public role in financing long-term services for low-income Americans. As beneficiaries, states, and providers continue to advance their own policy agendas, the DRA is an indication of emerging federal policy in this area.

Endnotes

¹ *Estimated Budgetary Effects of Title VI of S. 1932*, Congressional Budget Office Cost Estimate for S. 1932, Deficit Reduction Act of 2005 as amended and passed by the Senate on December 21, 2005, January 27, 2006.

² See Sections 6011-6016 of the Deficit Reduction Act of 2005.

³ O'Brien, E., *Long-Term Care: Understanding Medicaid's Role for the Elderly and Disabled*, Kaiser Commission on Medicaid and the Uninsured, November 2005.

⁴ *Eye on Elder Issues*, National Association of Elder Law Attorneys, December 2005, Vol. 2, Issue 7.

⁵ *Estimated Budgetary Effects of Title VI of S. 1932*, Congressional Budget Office Cost Estimate for S. 1932, Deficit Reduction Act of 2005 as amended and passed by the Senate on December 21, 2005, January 27, 2006.

⁶ See Section 6021 of the Deficit Reduction Act of 2005.

⁷ Alhstrom, A., Clements, E., Tumlinson, A., and Lambrew, J., *The Long-Term Care Partnership Program: Issues and Options*, Brookings Institution, December 2004.

⁸ *Estimated Budgetary Effects of Title VI of S. 1932*, Congressional Budget Office Cost Estimate for S. 1932, Deficit Reduction Act of 2005 as amended and passed by the Senate on December 21, 2005, January 27, 2006.

⁹ *Private Long-Term Care Insurance: A Viable Option for Low and Middle-Income Seniors?*, Kaiser Commission on Medicaid and the Uninsured, February 2006.

¹⁰ See Sections 6061 and 6062 of the Deficit Reduction Act of 2005.

¹¹ Refers to a state option established by the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA), Public Law 97-248.

¹² *Estimated Budgetary Effects of Title VI of S. 1932*, Congressional Budget Office Cost Estimate for S. 1932, Deficit Reduction Act of 2005 as amended and passed by the Senate on December 21, 2005, January 27, 2006.

¹³ *Letter to the Honorable Joe Barton regarding Medicaid provisions in S. 1932, the Deficit Reduction Act of 2005*, Congressional Budget Office, January 31, 2006.

¹⁴ See Section 6071 of the Deficit Reduction Act of 2005.

¹⁵ Crisp, S., Eiken, S., Gerst, K., and Justice, D., *Money Follows the Person and Balancing Long-Term Systems: State Examples*, Centers for Medicare and Medicaid Services, September 2003.

¹⁶ O'Brien, E., *Long-Term Care: Understanding Medicaid's Role for the Elderly and Disabled*, Kaiser Commission on Medicaid and the Uninsured, November 2005.

¹⁷ *Estimated Budgetary Effects of Title VI of S. 1932*, Congressional Budget Office Cost Estimate for S. 1932, Deficit Reduction Act of 2005 as amended and passed by the Senate on December 21, 2005, January 27, 2006.

¹⁸ *Letter to the Honorable Joe Barton regarding Medicaid provisions in S. 1932, the Deficit Reduction Act of 2005*, Congressional Budget Office, January 31, 2006.

¹⁹ See Section 6086 of the Deficit Reduction Act of 2005.

²⁰ Under Section 1915(c) of the Social Security Act, eight services are explicitly included in the HCBS waiver program, and states can choose to include or exclude these services: 1) case management; 2) homemaker services; 3) home health aide services; 4) personal care services; 5) adult day health services; 6) habilitation services; 7) respite care; and 8) day treatment and other partial hospitalization services, psychosocial rehabilitation services, and clinic services for individuals with chronic mental illness. States can also seek to cover, with federal approval, other services because they are needed to prevent waiver beneficiaries from needing to be placed in an institution, such as non-medical transportation, in-home support services, special communication services, minor home modifications, and adult day care. Except in limited circumstances, room and board cannot be covered.

²¹ Consortium for Citizens with Disabilities (CCD) letter to Senators, dated December 20, 2005 and National Council on Independent Living (NCIL) letter to Senators dated December 19, 2005.

²² Kitchener, M., Ng, T., Harrington, C., and Elias, R. *Medicaid Home and Community-Based Service Programs: Data Update*, Kaiser Commission on Medicaid and the Uninsured, July 2005.

²³ O'Brien, E., *Long-Term Care: Understanding Medicaid's Role for the Elderly and Disabled*, Kaiser Commission on Medicaid and the Uninsured, November 2005.

²⁴ *Kerr v. Holsinger*, No. Civ.A.03-68-H, 2004 WL 882203 (E.D.Ky. 2004)

²⁵ *Estimated Budgetary Effects of Title VI of S. 1932*, Congressional Budget Office Cost Estimate for S. 1932, Deficit Reduction Act of 2005 as amended and passed by the Senate on December 21, 2005, January 27, 2006.

²⁶ *Letter to the Honorable Joe Barton regarding Medicaid provisions in S. 1932, the Deficit Reduction Act of 2005*, Congressional Budget Office, January 31, 2006.

²⁷ See Section 6087 of the Deficit Reduction Act of 2005.

²⁸ For additional background information, see Crowley, J.S., *An Overview of the Independence Plus Initiative to Promote Consumer-Direction of Services in Medicaid*, Kaiser Commission on Medicaid and the Uninsured, November 2003.

²⁹ *Letter to the Honorable Joe Barton regarding Medicaid provisions in S. 1932, the Deficit Reduction Act of 2005*, Congressional Budget Office, January 31, 2006.

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