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Trading Places: Real Choice Systems Change Grants and the Movement to Community-Based Long-Term Care Supports

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OVERVIEW — *The Real Choice Systems Change grant program was created to help states transform their long-term care service systems from ones that rely on institutions to ones that are more community-based. The grants are intended to help states develop the infrastructure needed for seniors and individuals with disabilities to live in integrated community settings. This issue brief provides information about Systems Change grants and the kinds of activities state Medicaid agencies have undertaken to transform their institutionally based systems. In addition, this paper reports on some of the qualitative and quantitative responses to the changes. This brief also raises critical policy questions related to public spending for long-term care in different settings that might be considered in tandem with future grant funding decisions.*

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Trading Places: Real Choice Systems Change Grants and the Movement to Community-Based Long-Term Care Supports

Over the past three decades, states and the federal government have placed increasing emphasis on the development of community-based service options for the more than 3.6 million seniors and younger people with disabilities who use Medicaid long-term care services. A number of factors have driven the movement toward community-based supports. Consumers consistently express a preference for remaining in their own homes as participating members of their communities rather than being placed in institutional settings. Recent legal decisions have required that people with disabilities are not isolated in institutional settings when reasonable accommodation can be made in the community. States and federal governments also view community-based services as a way to control Medicaid long-term care spending. Although long-term care users comprise only 7 percent of the Medicaid population, they account for over half (52 percent) of total Medicaid spending.[1] In addition, the aging of the nation's population raises concerns about the sustainability of Medicaid long-term care spending for the future.[2] As long-term care expenditures consume an increasing share of the Medicaid budget, states are moving to increase the proportion of people who receive services in the community to meet consumer preferences and to help stem the rate of growth in spending.

In 2000, Congress enacted legislation authorizing the Real Choice Systems Change grant program to help states transform their long-term care service systems from ones that rely on institutions to ones that are more community-based. The grants, awarded annually from 2001 through 2006, are intended to help states develop the infrastructure needed for seniors and individuals with disabilities to live in integrated community settings. They are administered by the Centers for Medicare & Medicaid Services (CMS) as part of the Bush administration's New Freedom Initiative, which aims to encourage greater use of community-based services for people who traditionally have been served in nursing homes or other types of institutional settings.

Systems Change grants help states support a wide variety of activities in four major areas: efforts to improve access to existing services and supports; to create new services and supports; to design, implement, and maintain systems and processes that enable services, such as data or

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quality assurance systems; and to improve recruitment, training, and retention of direct service workers.[3] Since 2001, over $243 million in grants has been awarded to all 50 states, the District of Columbia, and four territories to support these activities. The average total awards to each state over the 2001–2006 period is about $4 million; however, the amount received by each state varies greatly (Appendix 1). Wisconsin has received the most funds: over $10 million. Arkansas, Michigan, North Carolina, New Hampshire, and Vermont have also received over $8 million each in grant funds. At the other end of the spectrum, South Dakota has received only about $200,000, and two territories, American Samoa and Puerto Rico, have each received $50,000.

Funds from these grants assist both states that are experienced with implementing community-based services and states that are just beginning to pursue community-based alternatives. More experienced states may use grant funds to improve ongoing activities, whereas less experienced states may use them to develop new community-based initiatives. To facilitate cross-fertilization of ideas, information about grant activities and promising practices has been widely shared among grantees and other stakeholders through Web sites established for that purpose, technical assistance, reports, and conferences. However, little evaluation has taken place on a national level to analyze the success of various initiatives. Reports on grant activities to date have primarily been descriptive of state activities, accomplishments, and challenges. Further, the sustainability of grant activities in the absence of grant funds may be difficult without a strong commitment from state leadership and strategies to fund initiatives. For example, many states that developed recommendations to strengthen the direct service workforce under their Systems Change grants have struggled to find additional funding to implement those recommendations.[4]

This issue brief provides information about Systems Change grants and the kinds of activities state Medicaid agencies have undertaken with the federal grant money. The paper highlights some state efforts to transform their institutionally based systems, and it reports on some of the qualitative and quantitative responses to the changes. Because a national evaluation requirement was not included in the early years of the Systems Change grants program, limited impact analysis is available at this time. This paper also raises critical policy questions related to public spending for long-term care in different settings that might be considered in tandem with future grant funding decisions.

BACKGROUND: FILLING THE GAPS IN LONG-TERM CARE

Medicaid is the primary financing mechanism for long-term care services in the United States, accounting for about 42 percent of all long-term care spending.[5] Initially, state Medicaid programs largely provided

long-term care services in institutional settings: nursing homes for seniors and younger adults with physical disabilities and large, mostly state-run institutions for people with developmental disabilities. In 1981, the enactment of the home and community-based services (HCBS) waiver program under section 1915(c) of the Social Security Act expanded the states' ability to provide services in the community. Growth of the HCBS waiver program was slow at first, mainly because of federal rules that limited the types of people who could be served, the types of services available and, perhaps most importantly, the number of people receiving services. A "cold bed" rule required states to demonstrate that an institutional bed was available for each waiver participant as a way to ensure cost neutrality. In states that had restrictions on building new nursing home beds, this requirement was a serious impediment to HCBS waiver growth.

The enactment of the ADA in 1990 and subsequent court rulings such as *Olmstead v. L.C.* (1999) have upheld the rights of people with disabilities to receive services in the most appropriate, integrated setting, rather than in institutions.

In the late 1980s through the early 1990s, Congress and CMS (known then as the Health Care Financing Administration) took a number of steps to relax federal requirements, including removal of the cold bed rule. Many states began to pursue community-based alternatives to institutional care, recognizing that Medicaid long-term care expenditures could be better controlled with 1915(c) waiver provisions that allowed states to cap the number of participants and the amount of spending per participant. Thus, the number of HCBS waiver programs began to grow. However, growth did not keep pace with demand, and waiting lists became common.

Meanwhile, consumers and their advocates pressed for even greater opportunities to receive services in their own homes and communities. Consumer demands were strengthened by the enactment of the Americans with Disabilities Act (ADA) in 1990 and subsequent court rulings such as *Olmstead v. L.C.* (1999) that have upheld the rights of people with disabilities to receive services in the most appropriate, integrated setting, rather than in institutions.[6] As a result of these influences, community-based care (that is, HCBS waiver services, personal care services, and home health care services) has grown from 14 percent of Medicaid spending in 1991 to 37 percent of spending in 2005. To date, there are over 260 HCBS programs in operation.[7] These efforts are often referred to as "rebalancing," or attempting to achieve a more equitable balance between the proportion of total Medicaid long-term care expenditures used for institutional services and those used for community-based supports.

Rebalancing efforts, however, have faced a number of challenges. Medicaid rules, originally designed for institutional settings, often do not lend themselves to community-based care delivery. For example, Medicaid eligibility rules in some states favor people who reside in institutional

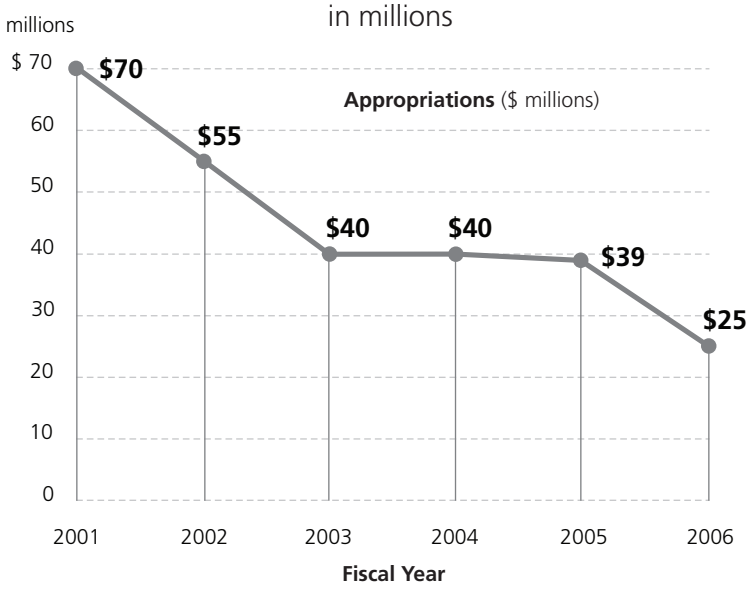
settings by applying more restrictive income eligibility criteria to people applying for HCBS waiver programs and allowing them to retain fewer assets. In addition, benefit definitions may not encompass the types of supportive services needed to live in the community; for example, respite services that provide relief for family caregivers are not a covered Medicaid service except when provided through a waiver. Medicaid HCBS waiver programs have proliferated, in part, as a way to circumvent some of the existing restrictions, as well as a way to achieve cost savings.

In 2001, the Bush administration launched the New Freedom Initiative to further promote community living for seniors and people with disabilities by coordinating existing resources and modifying policies to create incentives for community integration. As part of the Initiative, the U.S. Department of Health and Human Services (HHS) conducted a self-assessment of existing federal policies, programs, statutes, and regulations to identify barriers that impede community living and to recommend solutions. The assessment resulted in several policy clarifications, including one that permits HCBS waiver programs to cover one-time costs such as security deposits on apartments and utility set-up fees for people who are making the transition from institutions to community living arrangements.

While this greater regulatory and policy flexibility has helped individuals receive community-based services to some extent, many incentives still exist for consumers to be placed or to remain in institutions.[8] For instance, housing costs are not covered by Medicaid and can pose a significant barrier to community living for low-income elderly and disabled beneficiaries. Provider and direct service worker shortages in many areas of the country, lack of coordination among existing services, and budgetary limitations have also hampered states' ability to offer community-based services to more people. Lack of consumer awareness of available options can also limit the use of community-based services.

Legislation authorizing Systems Change grants was enacted by Congress to address some of these challenges. Congress has appropriated funds for these grants in gradually decreasing amounts each year from 2001 through 2006 (Figure 1). The grants are intended to assist states in developing the infrastructure necessary to support people of any age with a disability or long-term illness

FIGURE 1
Congressional Appropriations for Systems Change Grants,
in millions



Source: Federal Register notices, 2001–2006.

to live and participate in their communities. For example, states may use grants to develop new evaluation tools that are used to determine who is eligible to receive community services, test ways of diverting people from institutional settings and into communities, or recruit and train direct service workers.

Grant solicitations, published each year in the Federal Register, describe the requirements and parameters of the grants. Grant activities must focus on Medicaid-eligible populations and generally may not be used to fund direct services to beneficiaries.[9] Each grant remains available for either a three-year period (2001 through 2004 grants) or a five-year period (2005 and 2006 grants), although a state may apply for a no-cost extension if its funds have not been exhausted by the end of that period. In fact, most grantees have requested one-year extensions because grant start-up activities, such as competitive procurement of contractors, often proceed slower than initially anticipated. Grantees are required to make a nonfinancial contribution of 5 percent of the total grant award. This contribution may include the value of goods and/or services contributed by the grantee, such as salary and fringe benefits of staff devoting a percentage of their time to the grant. The grant solicitations strongly encourage the involvement of consumers in project design and implementation, including use of consumer task forces in developing grant applications and collaboration with a variety of organizations that advocate for seniors and people with disabilities, such as state independent living councils, area agencies on aging, developmental disabilities councils, state mental health planning councils, and state assistive technology act projects.

GRANT ACTIVITIES

Several types of grants have been offered each year, and states have been encouraged to apply for more than one type of grant. (Appendix 2 describes the types of grants and the years awarded.) The different types of grants are meant to address specific areas of concern that CMS identified through the self-assessment conducted under the New Freedom Initiative, National Listening Sessions, and Open Door Forums. For example, Community-Integrated Personal Assistance and Supports grants, awarded in 2001 through 2003 were designed to improve personal assistance services that are consumer-directed. Integrating Long-Term Care Supports and Affordable Housing grants awarded in 2004 were targeted to assist states in creating the infrastructure necessary to increase access to affordable and accessible housing. The types of grants awarded have changed over time as states' needs have changed and as more has been learned about the most effective way to offer grants.

In early 2001, CMS offered noncompetitive starter grants of $50,000 to each state. Forty-eight states, the District of Columbia, and four territories requested and received starter grants. After the starter grants, four

types of competitive grants were offered: Real Choice, Community-Integrated Personal Assistance Services and Supports, Nursing Facility Transition, and National Technical Assistance Exchange for Community Living. The response from states was overwhelming: 161 applications were received and over 50 awards were made in 2001. Because of the large number of proposals received, CMS did not accept new applications in 2002; the agency continued to award grants from the 2001 requests.

Eleven different types of grants were offered and funded in 2003, and ten types of grants were offered and funded in 2004. New types of grants were intended to promote and support specific aspects of states' long-term care systems such as quality assurance, respite care, and affordable housing. Another grant offered in 2003 through 2005 was earmarked not for state agencies, but for nonprofit organizations (with the endorsement of state Medicaid directors) to establish Family-to-Family Health Care Information and Education Centers (FHICs). These grants helped to establish family-run centers that disseminate information and training to families of children with special health care needs. (For more information, see text box, above).

Although each type of grant addresses a specific purpose, similar activities can be carried out under several different names. For example, systems that provide a single point of entry to long-term care services have been developed under Real Choice, Aging and Disability Resource Centers (ADRCs), and Rebalancing grants. CMS reduced the types of grants available in 2005 to three: Systems Transformation, ADRCs, and FHICs. Learning from experience in the prior four years, CMS designed the Systems Transformation grants to promote broad systems change rather than changes to small parts of systems. In 2006, only Systems Transformation grants were awarded, with some enhanced funding also provided to existing ADRC grantees. (For more information on ADRCs, see text box, next page.)

Family-to-Family Health Care Information and Education Centers

Families often lack knowledge about services and supports available for their children with special health care needs (CSHCN) and have trouble navigating the health care system to get those supports. Systems Change Grants awarded in 2003 through 2005, as well as grants from the Health Resources and Services Administration in 2002, have helped fund 25 Family-to-Family Health Care Information and Education Centers (FHICs) which are staffed to a large extent by parents who volunteer their time. FHICs educate families, help them make informed choices about services, and make referrals to service providers. FHICs also develop Web-based materials such as fact sheets and newsletters and take part in workshops and conferences.

Reliance on parents of CSHCN and volunteers means that staffing can be an issue for FHICs. There are also concerns about whether these programs can be sustained when grant funds run out. Many FHICs are applying for new grants or are exploring options such as becoming Medicaid providers or contracting with managed care organizations. The Deficit Reduction Act of 2005 appropriated $12 million in grants for FHICs, with the goal of establishing centers in all states by 2009.

More information on FHICs is available at www.familyvoices.org/info/ncfpp/f2fhic.php.

Aging and Disability Resource Centers

In 2003 through 2005, CMS joined with the Administration on Aging (AoA) to offer grants that help states develop Aging and Disability Resource Centers (ADRCs), which serve as one-stop shops to help people make informed decisions about the complete spectrum of long-term care options and create single entry points to their long-term care systems. Forty-three states have received Systems Change grants for ADRCs, and there are approximately 75 pilot sites operating around the country. According to AoA, by the fall of 2006, 104 ADRC pilot sites were opened, serving more than 600 counties where over 20 percent of the U.S. population resides. ADRC grantees must serve adults age 60 and over and at least one other target populations such as younger adults with physical disabilities or people with developmental disabilities. Systems Change grants represent only about 25 percent of annual budgets for ADRC pilot sites. Other sources of funding include the Older Americans Act, Medicaid, state and local revenue and other grants.

Consumers, caregivers and professionals access ADRC services through Web-based applications at some pilot sites, while other sites provide in-person and telephone assistance. A majority of ADRCs have developed Web-based, comprehensive resource databases and provide online access to program applications and allow electronic submission of application forms. ADRCs have also streamlined application processes by establishing standard screening and intake processes across the variety of organizations that deliver community-based services.

Source: The Lewin Group, The Aging and Disability Resource Center (ADRC) Demonstration Grant Initiative: Interim Outcomes Report, *prepared for U.S. Department of Health and Human Services, November 2006; available at www.adrc-tae.org/documents/InterimReport.pdf.*

Areas of Focus

Key activities that have taken place through all the years of grantmaking (and the primary categories of grants that support them) are as follows:

- **One-stop shops —** To increase consumers' knowledge about existing service options and help them navigate the long-term care system, many grantees are developing resources that integrate information about the array of services available within a particular area. These activities often involve developing Web sites or toll-free lines to access information and creating dedicated information, referral, and assistance staff positions. [*Real Choice, Rebalancing, and ADRC*]
- **Streamlining eligibility determinations —** Consumers often face a long and complex application process in order to access Medicaid long-term care services. The process involves determining whether an individual is both financially eligible (income and assets) and functionally eligible (that is, in need of long-term care services). These determinations are usually made by different entities within state government and often are not well coordinated. Some states are working on streamlining financial and/or functional eligibility determinations so that they appear seamless to consumers. Several states integrate the application process with one-stop shops so that there is one centralized location at which consumers apply for services and obtain information about and referrals to services. For example, Arkansas is developing a single, standardized assessment form to establish eligibility for both nursing facilities

and HCBS waiver programs.[10] The state is also developing a "fast track" process to reduce the eligibility wait time for processing Medicaid waiver applications. [*Real Choice, Rebalancing, and Systems Transformation*]

- **Consumer-directed services —** States that offer individuals the opportunity to direct their own services establish a state-approved budget for each consumer that he or she may use for the purchase of services. For example, the consumer may choose which services to purchase and may hire (and fire) workers who provide personal assistance services. States use grant funds to develop new consumer-directed waiver programs and to incorporate the principles of consumer direction into program rules. In Florida, grant funds were used to establish committees in each district to work with consumers enrolled in the state's section 1115 cash and counseling demonstration program. Committees were responsible for developing a district-wide plan to implement self-determination. Florida also collaborated with an advocacy organization, the Center for Self-Determination, to identify the content of a training curriculum designed to educate the district committees, support brokers, advocate groups, providers, and policymakers about consumer direction and self-determination.[11] [*Real Choice, Community-Integrated Personal Assistance Services and Supports, Living with Independence, Freedom and Equality Account Feasibility and Demonstration, Independence Plus, Rebalancing, and Systems Transformation*]
- **Nursing facility transition and diversion programs —** A number of states are using grant funds to develop ways to divert people from entering nursing homes or to move people out of nursing homes and into their own homes and communities (see text box, below). For example, New Jersey used grant funds to support visits to the state's nursing facilities and rehabilitation hospitals to explain the transition initiative to individuals and facility staff and to encourage support for patients in

A Consumer Perspective on Nursing Facility Transition

"Georgia has had a Real Choice [Nursing Facility] transition grant and during the past year or so, 124 people have moved out of facilities into their own home and communities. Great news and a very successful project! The IL [Independent Living] community…have been key to making this success. Along the way, as it happens, of the 124 people who moved out, 47 didn't need ongoing (Waiver) supports and services. They just needed the initial, up front transition assistance, including home modifications to make a successful move. These folks continue to benefit from and add to their communities with what are known as 'informal' and 'natural' supports. Community integration and informal and natural support, in this respect, come to mean the same thing and clearly, as this example demonstrates, are key to success, though often overlooked. In other words, the most successful integration occurs when an individual uses the same 'natural' services and supports available in a given community that everybody else uses, as opposed to only using 'special,' separate services and programs."

Source: Real Choice Systems Change Grant Consumer Task Force Technical Assistance Center, "Tips for Consumer Task Force Members"; available at www.tilrc.org/Real%20Choice%20Website/Real%20Choice%20Tips.htm.

the transition process. Other activities in New Jersey included providing information through brochures and a project Web site, providing assistance to hospital patients at highest risk of nursing home placement, connecting mentors in the community with nursing facility residents interested in community living, educating consumers and families on how to make informed choices and obtain quality services, and sharing expertise and knowledge with community organizations.[12] [*Nursing Facility Transitions, Rebalancing, and Systems Transformation*]

- **Affordable and accessible housing —** Lack of affordable housing is often a barrier to community living for seniors and people with disabilities. Individuals who have been in nursing homes for an extended period of time may have lost their existing homes, and the supply of housing for low-income individuals is seldom adequate. Some individuals may need modifications made to their homes to accommodate wheelchairs or other assistive devices. Some states are attempting to address the issue of affordable housing for seniors and people with disabilities by working with housing authorities and developers. Activities have included conducting educational campaigns, forming task forces to address housing barriers, helping consumers obtain rent subsidies, and improving access through home modification. For example, Nevada hired a housing development specialist to develop a down payment assistance program and a policy manual to help consumers with physical and mental impairments use the program.[13] [*Nursing Facility Transition, Integrating Long-Term Supports with Affordable Housing, and Systems Transformation*]
- **Quality assurance and quality improvement (QA/QI) —** Ideally, consumer-directed services lead to greater consumer satisfaction and improved outcomes, but consumer involvement is needed to determine whether such services are achieving the desired results. Many grantees are working to add a consumer focus to quality monitoring and management systems. For example, Colorado awarded grants to six self-advocacy and family advocacy groups to strengthen their efforts through technical assistance, cash, and in-kind support. The state also established a statewide committee of self-advocates to provide input to the director of the Division for Developmental Disabilities regarding policy and QA/QI issues, which will continue after the grant ends.[14] [*Quality Assurance and Improvement in HCBS, Rebalancing, Independence Plus, Comprehensive Systems Reform, and Systems Transformation*]
- **Flexible funding —** State budgets usually contain separate line items for nursing homes and community-based services. Whether a nursing home resident can transition to receiving community-based services often depends on whether there are sufficient funds in the HCBS budget, even though Medicaid funds are already being expended for nursing home services for that individual.[15] A number of grantees are changing their budgeting systems to permit the funds to follow the person regardless of where he or she resides. For example, Texas has legislation that moves money from the state's nursing facility

budget to the state's home and community-based services budget for people who transition into community settings. According to state officials, this law has helped over 12,000 people leave nursing facilities since September 2001.[16] A Money Follows the Person grant was used to create one facet of the Texas program: local systems in each of ten regions in the state that help clients transition from nursing homes to the community. Voluntary Nursing Facility Transition Teams composed of caseworkers, advocates, other agency personnel, local government employees, profit and nonprofit organizations, home health providers, housing authority representatives, and others assess individuals with complex needs who are requesting transition from the nursing facility to the community. Teams also establish transition plans based on those needs, offer technical assistance to consumers, secure resources, and assist in the transition itself. Grant funds have also assisted with education of state staff, consumers, advocates, and other stakeholders about the range of community care options available. Work on these grants led to the enactment of the Money Follows the Person Rebalancing Demonstrations (see "On the Horizon" section, below) as part of the Deficit Reduction Act of 2005. [*Money Follows the Person, Rebalancing, Comprehensive Systems Reform, and Systems Transformation*]

- **Recruitment, training, and retention of direct service workers —** Activities in this area have included promotional efforts through Web sites, brochures, career fairs, and worker registries. A few grantees have also developed training curricula to improve the skills of direct service workers. Others are conducting surveys of workers and collecting data about working conditions in an effort to increase the availability of workers. For example, Illinois worked to get new legislation passed that increased wages for personal care assistants.[17] Although these efforts have produced some innovative ideas, limited budgets often prevent implementation of strategies (such as improved salaries and benefits) and the effectiveness of various initiatives has not been evaluated.[18] [*Real Choice, Community-Integrated Personal Assistance Services and Supports, Comprehensive Systems Reform, and Nursing Facility Transition*]

National Technical Assistance Grants

In addition to grants awarded to states and their partners, National Technical Assistance Grants totaling over $17.5 million were also awarded to several organizations to provide technical assistance and training and to disseminate information to states, grantees, consumers, and the public. The National Technical Assistance Exchange for Community Living grant was awarded each year from 2001 through 2004 to two organizations: Rutgers Center for State Health Policy (2001, 2002, and 2003) and Independent Living Research Utilization (2001, 2002, and 2004).[19] These grants have resulted in the National Clearinghouse for the Community Living Exchange Collaborative (www.hcbs.org), which is a hub for information exchange among grantees. In addition to making a wealth of material available through its Web site,

the Clearinghouse provides on-site training and individualized technical assistance and conducts Web casts and conferences. One grant was also awarded in 2003 to the Topeka Independent Living Resource Center and a consortium of consumer-controlled organizations for Technical Assistance for Consumer Task Forces.[20] The purpose of this grant was to promote consumer involvement in state long-term care reforms.

EVALUATION OF GRANTS

While much has been written about the activities and promising practices undertaken by Systems Change grantees, there is little evaluative data available to determine the effect of the grants on states' rebalancing efforts. Real Choice Systems Change grants were intended as catalysts for developing new approaches to rebalancing Medicaid long-term care, but the authorizing legislation required national evaluations only for the grants awarded in 2005 and 2006. Although CMS has funded annual evaluations since the beginning of the program, these reports are largely descriptive of grantee activities. To some extent, the descriptive nature of the reports reflects both that the grants were in the early stages of implementation and that the outcomes of infrastructure changes are inherently difficult to measure, particularly when they are influenced by a variety of different factors. Final reports have been issued on 2001 grantee activities for the Nursing Facilities Transitions and Workforce Initiatives and on 2003 Money Follows the Person grantees.[21] In 2003, Congress also directed CMS to commission a study in up to eight states to explore the various management techniques and programmatic features that states have put in place to rebalance their Medicaid long-term care systems. A topic paper on states' organizational structures that support rebalancing has been completed on the basis of case studies of these states.[22] The three final reports and the topic paper all point to the need for empirical analyses to explore the success of new approaches.

There is little evaluative data available to determine the effect of the grants on states' rebalancing efforts.

It is important to recognize that activities supported with System Change grant funds often constitute only one piece of a state's larger rebalancing efforts. Changes seen are more likely the result of a confluence of different forces than of the Systems Change grants alone. For example, a lawsuit by five individuals with long-term care needs based on the *Olmstead* decision was a major factor in Louisiana's development of a nursing facility transition program.[23] In some states, such as New Jersey and Oregon, nursing facility transition activities were under way well before either the *Olmstead* decision or Systems Change grants because of leadership priorities in those states. In addition, rebalancing efforts have become more of a priority in many states because of rapidly rising Medicaid long-term care costs and states' recent fiscal crises.

While budget deficits led to tighter caps on HCBS waiver program placements in some states, transitions to the community continued in other

states under the assumption that lower community costs would save money in the long run. For example, community placements in Texas are done outside of HCBS waiver program caps and thus were not affected during the budget crisis. Analysts also point out that grant activities are more likely to be sustainable in states that have support from senior elected officials in state government, including governors and legislators.

State Reports and Consumer Perspectives

In annual reports on Systems Change grants, states have reported sustainable improvements that have helped with their rebalancing efforts, such as establishing new funding for transition services, increasing the number of available HCBS waiver slots, enacting new state laws, and making more outreach and educational materials available for consumers.[24] However, the final report on 2003 Money Follows the Person grantees points out that relatively few people have been transitioned to the community in comparison with the number of people residing in nursing facilities.[25] This observation is consistent with earlier studies (not specific to Systems Change grants) that examined the number of people who have returned to the community under nursing facility transition programs and generally found that the numbers were small—in the low hundreds annually for most states.[26] Notable exceptions are Texas and Washington state, which have both transitioned an average of about 2,400 people annually from nursing facilities to community-based settings, including individual homes, assisted living facilities, and adult group homes.

States also report that significant barriers to rebalancing still remain. A lack of accessible and affordable housing continues to prevent many people, particularly those who have low incomes, from residing in their own homes. The use of residential care or assisted living facilities may help address the lack of housing and also can provide a community-based alternative for individuals who need higher levels of supervision.[27] However, some consumer advocates view assisted living facilities as no different than nursing homes. (See text box, right.) In addition, many states do not cover services in residential care facilities under their HCBS waiver programs. Restrictions on available services, as well as a lack of services and direct service workers, remain problematic in many areas. Further, transitioning people from institutional facilities to community

A Consumer Perspective on Real Choice Philosophy and State of Mind

"'Beds,' 'slots,' number of 'beds' in a 'home,' 'allowing to choose,' 'care for,' are terms that continue to pop up as part of Real Choice projects around the country. Real choice must mean that seniors and individuals with disabilities have a right to not be an object of someone else's 'care,' professional attention, or control. Home and community does not mean that the only non-institutional living option is a group home, or a place with a 'home like' atmosphere. The issue is whether each person has control over decisions and the meaning of home and community. As long as individuals have to fit into beds, slots, programs, etc., then real choice does not exist and systems have not changed."

Source: Real Choice Systems Change Grant Consumer Task Force Technical Assistance Center, "Tips for Consumer Task Force Members."

settings is complex, requiring concerted effort and a significant commitment of administrative resources to find and coordinate the various needed supports and services from a fragmented delivery system. States have attempted to address these barriers through grant activities; however, some barriers are beyond the scope of the grants. For example, the low-income housing supply overall is unlikely to improve significantly despite grant activities that have helped to find ways to better coordinate Medicaid initiatives with local housing authority efforts.

Although many barriers to community living persist, expenditure data show that the distribution of spending between community-based long-term care services (including HCBS waivers, personal care, home health services) and institutional services is slowly but steadily changing. Community-based long-term care expenditures rose to 37 percent of all Medicaid long-term care costs in 2005, and this number continues to increase by one to three percentage points each year, as state Medicaid programs invest more resources in home and community-based services.[28] States also consistently report that nursing home transition programs are cost-effective, although there is no uniform way that the programs demonstrate cost effectiveness.[29]

Much less is known about the experiences of consumers who participate in programs that transition or divert people from institutional placement. Although the numbers of people who have been transitioned remains relatively small, these programs can have a large impact for individual consumers who are now able to live and participate in their communities. The final report on Money Follows the Person points out, however, that if adequate housing and community supports are not in place or are not provided at the level needed, consumer satisfaction may not be higher in the community than in an institutional setting and there is little empirical evidence either way.[30]

The state of New Jersey did conduct a study of its nursing facility transition program, which found that 93 percent of consumers were satisfied or somewhat satisfied with their current living situations in the community. [31] Those residing in facility-based community situations, such as assisted living facilities and group homes, reported more satisfaction with their place of residence than those who lived in their own homes or the homes of relatives, mostly due to greater opportunities to socialize with family and friends. Between 10 and 20 percent of individuals (most of whom were already receiving assistance, usually from an informal caregiver) indicated at least some unmet need for assistance with activities of daily living.

In addition, some early evaluation data has been produced by the ADRC grantee initiative. An interim report on the 2003 and 2004 ADRC grantees found that the average number of contacts per month across all sites increased by over 200 percent over a two-year period, and consumers expressed high levels of satisfaction with ADRC services. The analysis was limited, however, because the types of data collected varied significantly

across sites and few sites reported on access to services after ADRC contacts were made. Data from eight pilot sites in five states that reported consistent data show that there has been a 10.2 percent increase in HCBS enrollment and an 11.8 percent decline in institutional placements since instituting an ADRC. However, these data represent overall enrollment, not just enrollment among ADRC consumers, and it is unclear whether these trends are a direct result of ADRC initiatives.

Outstanding Questions

Clearly, state reporting on grant activities is valuable, but it can only provide limited information. In order for the Systems Change grants program to receive the sort of intensive and extensive evaluation and analysis that would provide better information, some critical policy questions about the grants specifically and public spending for long-term care in general would need to be addressed. These questions include

- Should the federal government continue funding such a wide array of grant activities, or should funds be focused on the most successful models? What are the costs and benefits of having diverse types of grants whose focus changes every year?
- Is it necessary to provide additional federal funds to continue state efforts to transform their systems to greater reliance on community care, or are states moving in this direction anyway?
- Given budgetary limitations, how can states meet the demand for services while assuring that individuals' needs and preferences are met?
- What measures are necessary to ensure an adequate workforce as the population ages and the demand for community-based services increases?
- What are the trade-offs between the higher value that individuals place on quality of life in a community setting versus potential quality of care problems, such as untrained caregivers or lack of needed care? What kind of oversight of caregiving is appropriate or necessary if public funds are expended in community- or home-based locations?

These types of questions should be addressed as the Systems Change grants move into maturity and special federal grant money is eliminated, leaving states to maintain programs with their regular Medicaid funds.

ON THE HORIZON

Building on the experience of the Real Choice Systems Change grants, the Deficit Reduction Act (DRA) of 2005 authorized $1.75 billion for Money Follows the Person Rebalancing demonstrations over the next five years (2007 through 2011). For these competitive grants, Congress defined Money Follows the Person more broadly than the traditional

budget-related definition. Section 6071 of Public law 190-171 states the goal of Money Follows the Person as "elimination of barriers or mechanisms, whether in state law, the state Medicaid plan, the state budget, or otherwise, that prevent or restrict the flexible use of Medicaid funds to enable Medicaid-eligible individuals to receive support for appropriate and necessary long-term services in the settings of their choice." The demonstration grants will support reforms that transition eligible individuals who have resided in nursing facilities for between six months and two years and will provide an enhanced federal matching rate for those individuals for one year after transition to the community. The enhanced federal matching funds are intended to serve as an incentive for states to transition more individuals. On January 12, 2007, CMS announced the first 17 states that will receive more than $23 million in grants for 2007.[32]

CONCLUSION

Leadership from the highest levels of federal and state government, strong advocacy by consumers, and budget-driven incentives to transform the long-term care system are important forces in rebalancing long-term care. While often funding only a small part of larger rebalancing efforts, Real Choice Systems Change grants have helped to support those efforts by prioritizing certain initiatives and by supplying funding for activities that may not have taken place in the absence of that support.

Much valuable information has been shared about individual state experiences, strategies, successes, and challenges through the Real Choice Systems Change grant program. However, analysis of the success of various initiatives has been hampered by the lack of a national evaluation strategy. That strategy could involve establishing indicators of success and measurable outcomes and identifying consistent sources of data across grantees with the goal of identifying approaches that work based on empirical evidence.

For the 2005 and 2006 grantees, CMS has established core performance measures on which states will be required to report and has contracted for a national evaluation to review and assess measures across states. Therefore, more definitive findings may become available from those evaluations. Further, the opportunity to receive enhanced federal matching funds (up to the grant amount) through the new Money Follows the Person demonstrations is likely to stimulate the transition of greater numbers of people to community-based settings. Tracking the outcomes for individuals who have been transitioned will be important to determine whether their needs are being adequately addressed and whether consumer satisfaction is higher in community-based settings. The answers to critical policy questions raised in this issue brief would help to determine the effectiveness of grants and advance the movement to community-based long-term care.

ENDNOTES

1. Anna Sommers, Mindy Cohen, and Molly O'Malley, "Medicaid's Long-Term Care Beneficiaries: An Analysis of Spending Patterns," Kaiser Commission on Medicaid and the Uninsured, Issue Paper, November 2006; available at www.kff.org/medicaid/upload/7576.pdf.

2. Projections indicate that, by the year 2020, the percentage of individuals age 65 and older will increase by one-third to 17 percent of the population—nearly 20 million more seniors than in 2000. Kathryn G. Allen, U.S. General Accounting Office (GAO), "Long-Term Care: Implications of the Supreme Court's *Olmstead* Decision Are Still Unfolding," GAO-01-1167T, testimony before the Special Committee on Aging, U.S. Senate, September 24, 2001; available at www.gao.gov/new.items/d011167t.pdf.

3. Angela Greene *et al., Real Choice Systems Change Grant Program Third Year Report: Progress and Challenges of the FY 2002 and FY 2003 Grantees (October 1, 2003 – September 30, 2004)*, RTI International, prepared for the Centers for Medicare & Medicaid Services (CMS), August 2005; available at www.cms.hhs.gov/RealChoice/downloads/2004report.pdf.

4. Wayne L. Anderson *et al., Direct Service Workforce Activities of the Systems Change Grantees Final Report*, RTI International, prepared for CMS, April 2004; available at www.hcbs.org/files/35/1708/CMSWorkforce.pdf.

5. Kaiser Commission on Medicaid and the Uninsured, "Medicaid and Long-Term Care Services," Medicaid Facts, July 2006; available at www.kff.org/medicaid/upload/Medicaid-and-Long-Term-Care-Services-PDF.pdf.

6. For more information on *Olmstead v. L.C.*, see Randy Desonia, "Is Community Care a Civil Right? The Unfolding Saga of the *Olmstead* decision," National Health Policy Forum, Background Paper, March 12, 2003; available at www.nhpf.org/pdfs_bp/BP_Olmstead_3-03.pdf.

7. Kaiser Commission on Medicaid and the Uninsured, "Medicaid and Long-Term Care Services."

8. For more information about challenges to increasing the use of HCBS see Cynthia Shirk, "Rebalancing Long-Term Care: The Role of Medicaid Home and Community-Based Services Waiver Program," National Health Policy Forum, Background Paper, March 3, 2006; available at www.nhpf.org/pdfs_bp/BP_HCBS.Waivers_03-03-06.pdf.

9. Under the Integrating Long-Term Care Supports and Affordable Housing grants awarded in 2004, a small percentage of funds were permitted to be used toward one-time transition costs, such as rental security deposits.

10. CMS, "Real Choice Systems Change Grants Compendium Fifth Edition," March 2006; available at www.cms.hhs.gov/RealChoice/downloads/compendium.pdf.

11. Greene *et al., Real Choice Systems Change Grant Program Third Year Report*.

12. Greene *et al., Real Choice Systems Change Grant Program Third Year Report*.

13. Greene *et al., Real Choice Systems Change Grant Program Third Year Report*.

14. Greene *et al., Real Choice Systems Change Grant Program Third Year Report*.

15. Most states limit the number of slots that are available in section 1915(c) HCBS waiver programs. When slots are filled, consumers are placed on a waiting list for services.

16. Marc Gold, Texas Department of Aging and Disability Services, telephone conversation with author, December 2006.

17. Kristen Siebenaler *et al., Real Choice Systems Change Grant Program: Second Year Report (October 1, 2002 – September 30, 2003)*, RTI International, prepared for CMS, September 2004; available at www.hcbs.org/files/51/2548/SystemsChange.pdf.

18. Anderson *et al., Direct Service Workforce Activities of the Systems Change Grantees*.

Endnotes / continued ➤

Endnotes / continued

19. The name of this grant was changed to "National State-to-State Technical Assistance Program for Community Living" in 2003 and 2004.

20. The Topeka Independent Living Center Web site can be accessed at www.tilrc.org/Real%20Choice%20Website/Real_Choice_Homepage.htm.

21. Janet O'Keeffe *et al., Real Choice Systems Change Grant Program FY 2001 Nursing Facility Transition Grantees: Final Report*, RTI International, prepared for CMS, August 2006, available at www.hcbs.org/files/96/4791/NFTGrantee.pdf; Anderson *et al., Direct Service Workforce Activities of the Systems Change Grantees*; and Wayne Anderson, Joshua M. Wiener, and Janet O'Keeffe, *Money Follows the Person Initiatives of the Systems Change Grantees: Final Report*, RTI International, prepared for CMS, July 2006; available at www.hcbs.org/files/96/4769/MFP.pdf.

22. Rosalie Kane *et al.*, "State Long-Term Care Systems: Organizing for Rebalancing," CNAC Corporation, prepared for CMS, December 2006; available at www.cms.hhs.gov/NewFreedomInitiative/downloads/Rebalancing_Topic_Paper_2.pdf.

23. Judy Kasper and Molly O'Malley, "Nursing Home Transition Programs: Perspectives of State Medicaid Officials," Kaiser Commission on Medicaid and the Uninsured, April 2006; available at www.kff.org/medicaid/upload/7484.pdf.

24. O'Keeffe *et al.*, *Real Choice Systems Change Grant Program FY 2001 Nursing Facility Transition Grantees*.

25. Anderson, Wiener, and O'Keeffe, *Money Follows the Person Initiatives of the Systems Change Grantees*.

26. Kasper and O'Malley, "Nursing Home Transition Programs."

27. It should be noted that Medicaid pays for services only, not for room and board. Congregate living facilities may provide a lower cost alternative to renting or buying private individual residences because of economies of scale.

28. Brian Burwell, Kate Sredl, and Steve Eiken, "Medicaid Long-term Care Expenditures in FY 2005," Thompson-Medstat, memo, July 5, 2006; available at www.hcbs.org/files/94/4687/Memo.pdf.

29. Leslie Hendrickson and Susan C. Reinhard, "Money Follows the Person: State Approaches to Calculating Cost Effectiveness," Rutgers Center for State Health Policy, Discussion Paper, September 2006; available at www.hcbs.org/files/97/4838/MFPCostEffectivenessFinal090506.pdf.

30. Anderson, Wiener, O'Keeffe, *Money Follows the Person Initiatives of the Systems Change Grantees*.

31. Sandra Howell-White, "Current Living Situation and Service Needs of Former Nursing Home Residents: An Evaluation of New Jersey's Nursing Home Transition Program," Rutgers Center for State Health Policy, June 2003; available at www.hcbs.org/files/19/907/CurrentLivingSituation1yearPostNJsNFTprogram.pdf.

32. CMS, "CMS Awards Demonstration Grants to 17 States for Alternatives to Institutional Care," press release, January 12, 2007. The 17 states are: Wisconsin, New York, Washington, Connecticut, Michigan, Oklahoma, Arkansas, Maryland, Nebraska, New Hampshire, California, Indiana, Texas, South Carolina, Missouri, Iowa, and Ohio.

APPENDIX 1
Total Systems Change Grants Awarded to States and Territories, 2001 through 2006 (in thousands of dollars)

State	Total Awarded*	State	Total Awarded*
AK	$ 4,503	MS	3,287
AL	4,170	MT	3,306
AR	8,058	NC	8,062
AS	50	ND	1,400
AZ	2,000	NE	4,220
CA	6,872	NH	8,425
CO	4,486	NJ	6,380
CNMI	1,635	NM	5,120
CT	3,669	NV	3,741
DC	4,101	NY	5,019
DE	2,739	OH	4,159
FL	3,872	OK	2,585
GA	4,169	OR	6,927
GU	1,823	PA	4,230
HI	2,925	PR	50
IA	4,521	RI	5,515
ID	3,366	SC	7,011
IL	2,050	SD	200
IN	4,359	TN	4,088
KS	5,159	TX	4,630
KY	3,000	UT	1,985
LA	6,896	VA	3,471
MA	7,624	VT	8,558
MD	3,459	WA	3,778
ME	7,372	WI	10,472
MI	8,558	WV	3,664
MN	4,792	WY	1,450
MO	6,048	TOTAL	$ 243,691,000**

** All numbers have been rounded to the nearest thousand dollars.*
*** Total does not equal the sum of the numbers above due to rounding.*

Sources: Martin Kitchener et al.*, "Federal Systems Change Grants to States and Territories," UCSF National Center for Personal Assistance Services, December 2006, available at http://pascenter.org/systemschange/index.php; Centers for Medicare & Medicaid Services, "Real Choice Systems Change Grants Compendium Fifth Edition," March 2006, available at www.cms.hhs.gov/RealChoice/downloads/compendium.pdf; and U.S. Department of Health and Human Services, "States Get Federal Grants To Help People With Disabilities Live in The Community," press release, September 15, 2006, available at www.cms.hhs.gov/RealChoice/downloads/ST_PressRelease_091506.pdf.*

APPENDIX 2: Systems Change Grants Awarded 2001–2006

Grant Type	Description	2001	2002	2003	2004	2005	2006
Real Choice	To promote partnerships between states and communities to expand and improve community-based long-term care systems.	X	X				
Community-Integrated Personal Assistance Services and Supports	To improve consumer-directed personal assistance services and provide maximum consumer control.	X	X	X			
Nursing Facility Transition	Two types: (i) To promote partnerships between states and Independent Living Centers that provide supports, and (ii) To help individuals make the transition from nursing facilities to the community, for example, through development of housing strategies.	X	X				
Respite for Adults	To assess feasibility of developing respite projects for caregivers of adults and to offer the opportunity for consumer direction.			X			
Respite for Children	To assess feasibility of developing respite projects for caregivers of children and to offer the opportunity for consumer direction.			X			
Community-Based Treatment Alternatives for Children	To develop community-based mental health services for children with serious emotional disturbances.			X			
Quality Assurance and Quality Improvement in HCBS	To develop systematic methods to meet statutory requirements and develop improved methods to involve consumers in quality assurance systems.			X	X		
Independence Plus	To assist states in meeting CMS expectations for approval of self-directed 1115 waiver programs.			X			
Money Follows the Person	To reform financing arrangements to enable individuals to make the transition between institutions and the community.			X			
Family-to-Family Health Care Information Centers	To establish family-run centers that provide education and training for families with children with special health care needs, develop and disseminate information, collaborate with other centers, and promote the philosophy of individual and family-directed supports.			X	X	X	

Note: This list does not include National Technical Assistance Grants.

Appendix 2 — continued >

APPENDIX 2: Systems Change Grants Awarded 2001–2006 *(continued)*

Grant Type	Description	2001	2002	2003	2004	2005	2006
Aging and Disability Resource Centers	To develop one-stop shops that help consumers make informed decisions about their support options and provide a single point of entry to long-term care services.			X	X	X	
Portals from EPSDT* to Adult Supports	To support innovative practices in screening, assessment and transition for consumers moving from children's services to adult services.				X		
Rebalancing Initiative	To develop and implement strategies that increase the availability of community supports.				X		
LIFE Accounts Feasibility and Demonstration**	To study the feasibility of savings programs that would enable consumers to control their own HCBS.				X		
Comprehensive Systems Reform	To develop and implement comprehensive long-term care reform plans.				X		
Integrating Long-term Care Supports and Affordable Housing Grants	To coordinate housing with long-term care services and increase availability of accessible housing for people using HCBS.				X		
Mental Health: Systems Transformation	To improve the availability of consumer-directed services for consumers with mental illness.				X		
Systems Transformation	To improve access, consumer-directed services, quality, information technology, HCBS funding and coordination with housing.					X	X

Note: This list does not include National Technical Assistance Grants.

**EPSDT is the Early and Periodic Screening, Diagnosis and Treatment program in Medicaid.*

***Living with Independence, Freedom and Equality (LIFE) is a personal savings account program begun under the New Freedom Initiative in 2004.*

Source: Kitchener et al., *"Federal Systems Change Grants to States and Territories."*