State Efforts to Rebalance Their Long Term Support Systems and Enable "Money to Follow the Person"

The purpose of this resource paper is to offer ideas and links to state initiatives that promote the principle of "money following the person." It is a "work in progress." We do not presume to have complete information on the very many initiatives states have undertaken. Further, the examples reflect only state initiatives for which we have been able to gather basic information and internet addresses that may enable the reader to access more detailed information. We invite comments on the resource paper and suggestions for future work.

Background

Passage of section 1915(c) of the Social Security Act in 1981 permitted states to develop community-based programs that support the ability of elderly and people of any age who have a disability to live and participate in their communities. The community programs also allowed states to reduce their predominant reliance on institutional forms of service and offer their citizens more choices for how they could live.

State efforts to "rebalance" their long term support systems have met with visible success. According to financial reports sent to CMS (the "HCFA 64" reports), only 4% of all Medicaid spending for long term support was devoted to community programs in 1981. This figure gradually rose to 29% in 2001. However, there is tremendous variation between states. Many states still have very limited community capacity.

In addition to "rebalancing" efforts, some states have also taken steps to redesign their long term support systems so that money and services are not tied to specific provider types or budget categories. Instead, funds are available to follow an individual across service settings and adapt to changes in the types of support that an individual may need over time.

Recent Developments: 2004 Budget Proposal for "Money Follows the Person"

In testimony before the House Committee on Energy and Commerce on February 12, 2003, HHS Secretary Tommy Thompson explained the President's $1.75 billion "Money Follows the Person- Rebalancing Initiative:"

> "Home and community-based care as an alternative to nursing homes for the elderly and disabled is a priority of this Administration. The *New Freedom Initiative* represents part of the Administration's effort to make it easier for Americans with disabilities to be more fully integrated into their communities. Under this initiative, we are committed to promoting the use of at-home and community-based care as an alternative to nursing homes.
>
> "It has been shown time and again that home care combines cost effective benefits with increased independence and quality of life for recipients. Because of this, we have proposed that the FY 2004 budget support a five-year demonstration

called “Money Follows the Individual” Rebalancing Demonstration, in which the Federal Government will fully reimburse States for one year of Medicaid home and community –based services for individuals who move from institutions into home and community-based care. After this initial year, States will be responsible for matching payments at their usual Medicaid matching rate. The Administration will invest $350 million in FY 2004, and $1.75 billion over 5 years on this important initiative to help seniors and disabled Americans live in the setting that best supports their needs.”

Since introduction of the President’s 2004 proposed budget, we have received many questions regarding steps that states could take to promote the principle of ‘money following the person.” Perhaps the best way to address this question is to look at some of the advances made by a diverse array of states across the country.

In the following material we highlight a few examples of actions different states have taken that promote either the principle of “money following the person,” or the goal of “rebalancing the long term support system” so that people have more choices. The examples below are not necessarily representative of the wide diversity of state initiatives. They are simply case examples of which CMS is aware and been able to collect some basic information. We are interested in more examples for what we regard as a continuing “work in progress.”

State actions to adopt more “person-centered” approaches to long term care might be described in terms of:

- **Access** to the system and to services,
- **Financing** of programs and services,
- **Services** and how and who delivers them, and
- **Quality**.

A. Access

People who need long term support are often confronted by a confusing array of different programs, each of which provides only a small part of the help that is needed. Each program also comes with its own logic, vocabulary, and differing eligibility requirements. People often move to nursing facilities because they are unaware of the alternatives, or cannot piece together disjointed community services into a coherent program that can help them remain at home.

Some states have begun to address these problems by offering a coherent source of **information**, in one place, about all the long term support services available and how to access them. Some states offer both **information and assistance,** such as crisis intervention, help with eligibility determination, contacting providers, choice and benefits counseling, or protection and advocacy. Some states have adopted **single entry points**, either for (a) all community programs regardless of funding source, or (b) all community and institutional programs. Such single entry points include authority to enable admission to programs. A few states been able to combine all of these elements

into **comprehensive access** that offers a truly person-centered way of streamlining access to all aspects of the long term support system.

Information

- **Florida**
  Telephone-based Clearinghouse on Disability Information (1-877-ADA-4-YOU) is a comprehensive single point of contact/inquiry to obtain information and links to state and local long-term care resources.
- **Hawaii**
  Web-based Single Entry Point (SEP) provides an interactive assessment, a database of all public and private long-term care services in the State with current openings and availability, and a quality assurance component to track gaps between requests and available services. www.realchoices.org

Information and Assistance

- **Illinois**
  Coordinated eligibility determination, funding sources, and case management simplify access to HCBS. http://cms.hhs.gov/promisingpractices/ilsa.pdf
- **New Jersey**
  Single entry system for long-term supports and the establishment of one statewide toll-free information and referral number increase access to information and services. http://cms.hhs.gov/promisingpractices/njsap.pdf

Single Entry Points for Community Programs

- **Indiana**
  For older persons and persons with physical disabilities, area agencies on aging serve as the single entry point for all long term care services funded by the Medicaid Home and Community Based Services Waiver, the state-funded Choice program and the Older Americans Act. http://www.in.gov/fssa/elderly/aging
- **Developmental Disabilities:** In the field of developmental disabilities, most states offer common access to most community programs.

Comprehensive Single Entry Point for All Long Term Support Services

- **Colorado**
  Single Entry Point (SEP) agencies serve as an access point for publicly-funded long-term care, educate individuals about service options, and simplify access to nursing facility alternatives. http://cms.hhs.gov/promisingpractices/cosa.pdf
- **Wisconsin**
  Aging and Disability Resource Centers provide information about community supports and serve as a single point of entry for home and community-based waivers and Medicaid State Plan services, including publicly financed nursing facilities, ICFs-MR and residential programs. The Resource Centers extend beyond information and assistance, to include person-centered assessments, emergency intervention, prevention activities, Medicaid eligibility determinations, and access to comprehensive

services from multiple funding sources.
http://cms.hhs.gov/promisingpractices/wioss.pdf
http://www.dhfs.state.wi.us/LTCare/Generalinfo/RCs.htm

B. Financing

Some states have improved the responsiveness of their finance systems by providing **linkages** between budget categories that are otherwise fixed and inflexible. For example, the Texas legislature passed legislation that directed a state agency to move money from the nursing facility state budget to the home and community-based waiver budget when an individual transitioned from a nursing facility to the community. Similarly, Wisconsin passed a law specifying that if a nursing facility voluntarily "de-licensed" a nursing facility bed, then a home and community-based waiver could be created and funded without going through the state budget process.

Some states have combined funding from different Medicaid categories into one flexible funding source that can provide help for a person regardless of setting. Such integrated or **"seamless funding"** enables "money to follow the person" so that people get the help they need, where they need it, and how they desire it.

Some states have promoted more flexible funding through the use of **individualized, self-directed budgets.** Under these arrangements, individuals work with the state program to determine the number and type of services that they will self-direct. The individualized budgets afford such persons, or their families, with more discretion over services. The extent to which such arrangements promote "money following the person" depends partly on how many services and the scope of services that are included.

Finally, some states have taken action to **rebalance** their systems through administrative actions that reduce reliance on institutional forms of service and build up more community capacity. Such actions do not necessarily enable money to follow the person, but can make the system more responsive by offering a more balanced array of choices.

Linkage Legislation

- **Texas**
  2001 state appropriations act "Rider 37" allows Medicaid funding to follow an individual who moves from a nursing facility to the community.
  http://cms.hhs.gov/promisingpractices/tx-rider37.pdf
- **Vermont**
  1996 legislative act shifts resources toward a broad array of home and community-based services. Under Act 160, as more people choose to receive services outside nursing facilities, more funding is available for programs that promote community and independent living. http://cms.hhs.gov/promisingpractices/vt-divdol.pdf
- **Wisconsin**
  Wisconsin passed a law specifying that if a nursing facility voluntarily "de-licensed" a nursing facility bed, then a home and community-based waiver could be created and funded without going through the state budget process.

Individualized Budgets

- **Arkansas**
  Cash and Counseling Demonstration http://cms.hhs.gov/promisingpractices/arca.pdf
  Independence Plus (1115) http://cms.hhs.gov/medicaid/1115/arwaiversum.pdf
- **Florida**
  Cash and Counseling Demonstration http://cms.hhs.gov/promisingpractices/flca.pdf
  Independence Plus (1115) http://cms.hhs.gov/medicaid/1115/flcdcipamdappran.pdf
- **New Jersey**
  Cash and Counseling Demonstration http://cms.hhs.gov/promisingpractices/njca.pdf
  Independence Plus (1115) http://cms.hhs.gov/medicaid/1115/njccfact.pdf
- **New Hampshire**
  Independence Plus (1915c) http://cms.hhs.gov/medicaid/1915c/nh0397apl.pdf
- **South Carolina**
  Independence Plus (1915c) http://www.hhs.gov/news/press/2003pres/20030311.html
- **Oregon**
  Pilot project enables Medicaid-eligible individuals to manage a cash budget for personal care and related services. http://cms.hhs.gov/promisingpractices/ormpc.pdf
- **Wyoming**
  Strategy determines individualized, equitable expenditure limits for home and community based services and systems that allows local planning teams to negotiate provider payment rates. http://cms.hhs.gov/promisingpractices/wyib.pdf

Seamless Financing

- **Florida**
  Pilot project provides Managed Care Organizations with financial incentives to expand community care and limit nursing facility care.
  http://cms.hhs.gov/promisingpractices/flpmco.pdf
- **Michigan**
  Project combines several funding streams into one managed care contract.
  http://cms.hhs.gov/promisingpractices/mipcp.pdf
- **New Hampshire**
  Almost all persons with developmental disabilities receive long term supports in the community as a result of state initiatives to dramatically increase home and community based services in conjunction with the closure of the state's large ICF/MR institution.
  http://www.dhhs.state.nh.us/DHHS/DSS/default.htm
- **Oregon**
  One of the true pioneers in promoting the ability of money to follow the person in a responsive long term support system, Oregon integrated the budgets for nursing facilities and home and community-based services at the state level, and reorganized state government to put all of the major long term support services for elderly and people with a disability under one management. While funding for institutional and community services were not integrated at the point of service delivery, they were integrated at the state level. This permitted the state to move funds between service categories as individuals expressed their preferences for different services. Oregon

combined these finance arrangements with single point entry into the system so that people are aware of all their choices. These and other actions enabled Oregon to achieve one of the most balanced systems in the country and one of the lowest rates of institutional use.http://www.sdsd.hr.state.or.us/pubs/03-09-1998.pdf

- **Washington**
  Washington adapted many of the features of Oregon's system combined with additional efforts, including substantial funding increases for home and community based services. These, together with the availability of financial resources to help persons transition from institutions to the community, have significantly reduced the number of persons receiving supports in nursing homes.
  http://cms.hhs.gov/promisingpractices/wa-offvar.pdf
- **Wisconsin**
  "Family Care" combines budgeting for all non-acute Medicaid state plan services (e.g. home health, nursing facilities, ICF-MR) with all home and community-based waiver funds into one flexible package that can support a person regardless of setting, based on each person's individualized plan. The program is implemented in pilot counties that account for about 30% of the state's population. The "Resource Centers" of Family Care provide single point access to the entire system, while "Care Management Organizations" provide a package of comprehensive, flexible services.
  http://www.cms.hhs.gov/promisingpractices/wifamcare.pdf

System Rebalancing

- **New Jersey**
  Increased HCBS services and decreased nursing facility utilization resulted from reorganization of state departments and changes in approach to consumer education and quality initiatives.
  http://www.milbank.org/reports/030314newjersey/030314newjersey.html

C. Services

When "money follows the person" in the long-term support system, services, supports, and financing move with the person to the most appropriate and preferred setting. They can change as his or her needs change. It is a market-based approach that gives individuals more choice over the location and type of service they receive.

By making the individual the focus of decision-making, funding, and methods by which services are organized, he or she is able to make more cost-effective decisions. For example, many individuals willingly substitute more effective or less costly services in lieu of traditional or overly medicalized services, when given the choice.

States have invented many methods to assure that all services are mobilized in support of what the individual needs and prefers, are effectively coordinated, include transition features (e.g. discharge planning) from one service or setting to another so that there is continuity of service, include emergency back-up arrangements to prevent breakdowns in services, and incorporate safeguards to ensure that individuals do not "fall through the cracks" between service categories.

Some states have addressed this challenge by "**flexible service integration**" where a single organization is responsible for all supports for an individual and can make adjustments to services as needed. Even though most individual services may by provided by subcontracts, there is one overarching organization responsible for ensuring that all services work effectively together and that new services are developed or adapted when needed by the individual.

Other states have adopted "**self directed services**" as a method to promote the ability of services to follow the person, although usually there are many services that remain outside the scope of the self-directed service package. Therefore, some states have combined the concept of a single organization responsible for ensuring the adequacy of services, together with a self-directed service option nested within the larger program.

Service management systems (sometimes labeled "case management" or "care management"), as well as support brokerage for self-directed services, represent an essential tool for enabling services to follow the person effectively. We have not included such features in this resource paper. We expect future papers to include service management systems and support brokerage, and are seeking advice on promising practices that particularly merit sharing among states.

Flexible Service Integration for Long Term Support

- See the examples under the "Seamless Financing" section of this paper

Self-Direction and Person Centered Planning

- **Alaska**
  Consumer-directed personal care agencies increase self-direction.
  http://cms.hhs.gov/promisingpractices/alchange.pdf
- **Arkansas**
  Cash and Counseling Demonstration http://cms.hhs.gov/promisingpractices/arca.pdf
  Independence Plus (1115) http://cms.hhs.gov/medicaid/1115/arwaiversum.pdf
- **Florida**
  Cash and Counseling Demonstration http://cms.hhs.gov/promisingpractices/flca.pdf
  Independence Plus (1115) http://cms.hhs.gov/medicaid/1115/flcdcipamdappran.pdf
- **Georgia**
  Voucher program increases family-direction of services.
  http://cms.hhs.gov/promisingpractices/gaisf.pdf
- **Michigan**
  State offers a wide array of services, emphasizes person-centered planning, and combines funding sources. http://cms.hhs.gov/promisingpractices/mipcp.pdf
- **New Jersey**
  Cash and Counseling Demonstration http://cms.hhs.gov/promisingpractices/njca.pdf
  Independence Plus (1115) http://cms.hhs.gov/medicaid/1115/njccfact.pdf
- **New Hampshire**
  Independence Plus (1915c) http://cms.hhs.gov/medicaid/1915c/nh0397apl.pdf
- **South Carolina**
  Independence Plus (1915c) http://www.hhs.gov/news/press/2003pres/20030311.html

- **Oregon**
  Pilot project enables Medicaid-eligible individuals to manage a cash budget for personal care and related services. http://cms.hhs.gov/promisingpractices/ormpc.pdf
- **Wyoming**
  Strategy determines individualized, equitable expenditure limits for home and community based services and systems that allows local planning teams to negotiate provider payment rates. http://cms.hhs.gov/promisingpractices/wyib.pdf

Coordination
- **Ohio**
  Electronic communication program between case managers and providers streamlines provider identification. http://cms.hhs.gov/promisingpractices/ohita.pdf

Continuity
- **North Dakota**
  Program that uses state funds to pay family members for their caregiving services increased consumer choice and control.
  http://cms.hhs.gov/promisingpractices/ndsfc.pdf

D. Quality Improvement

CMS, together with key State Associations, is only beginning to inventory promising practices in quality assurance and quality improvement that operate in a person-centered manner. However, below are examples of initiatives that retool quality improvement systems and/or governance models to enhance quality of life, stakeholder involvement, and inter-agency coordination.

Administering Programs with Active Involvement of Program Participants
- **Arkansas**
  Cash and Counseling Demonstration program greatly improved satisfaction and reduced most unmet needs and did not adversely affect participants' health and safety (March 2003 monograph).
  http://www.healthaffairs.org/WebExclusives/Foster_Web_Excl_032603.htm
- **Massachusetts**
  Culturally competent self-determination promoted with the establishment of community governing boards. http://cms.hhs.gov/promisingpractices/mafcc.pdf

Quality Assurance Involving Participants and Community Members
- **Minnesota**
  Participants, their families, advocates, providers, and county staff in the quality are central to the quality assurance review process for licensed services.
  http://cms.hhs.gov/promisingpractices/mnqi.pdf

Additional Resources

- **Evaluation of Cash and Counseling Demonstration projects**:
  http://www.mathematica-mpr.com/3rdLevel/cashcounseling.htm
  http://www.hhp.umd.edu/AGING/CCDemo/info.html

- **Promising Practices in Long Term Care Reform: Pennsylvania's Transformation of Supports for People with Mental Retardation**
  Pennsylvania's comprehensive restructuring of its practices creates a participant-driven system. The state's Transformation Project addresses quality, consumer support, and financial processes (March 3, 2003 monograph).
  http://www.cms.hhs.gov/promisingpractices/patspmr.pdf

- **August 13, 2002 State Medicaid Directors' letter**
  This letter focuses on strategies available to states under current authority to assist individuals to avoid or leave unnecessary nursing facility placement. This letter highlights promising state practices, such as programs in which money follows the person and outlines some early lessons learned from a nursing facility transition grant program. http://www.cms.hhs.gov/states/letters/smd81302.pdf

Key Building Blocks of a System in Which Money Can Follow the Person