



## Forum Session Meeting Announcement

**Friday, November 7, 2008**  
11:45am–12:15pm — Lunch  
12:15–2:00pm — Session

# Long-Term Services and Supports: Consumers in Charge—Consumer Direction and Money Follows the Person

### A Discussion Featuring:

**Joshua M. Wiener, PhD**  
*Senior Fellow and Program Director*  
Aging, Disability, and Long-Term Care  
RTI International

**Herb Sanderson**  
*Associate State Director for Advocacy*  
AARP Arkansas

**Marc Gold**  
*Director*  
Promoting Independence Initiative  
Texas Department of Aging and Disability Services

**Maureen Hollowell**  
*Director*  
Advocacy and Services  
Independence Center  
Norfolk, Virginia

### Location

**Reserve Officers Association  
of the United States**  
One Constitution Avenue, NE  
Congressional Hall of Honor  
Fifth Floor  
(Across from the Dirksen Senate  
Office Building)

### Registration Required

Space is limited. Please respond  
as soon as possible.

Send your contact information  
by e-mail to: [nhpfmeet@gwu.edu](mailto:nhpfmeet@gwu.edu)

THE GEORGE  
WASHINGTON  
UNIVERSITY  
WASHINGTON DC

# Long-Term Services and Supports: Consumers in Charge—Consumer Direction and Money Follows the Person

## OVERVIEW

*Many Medicaid beneficiaries with disabilities have limited choices about their living arrangements and services they need to live independently. They access personal care services primarily from Medicaid-approved agency providers; if consumers are eligible for a broader array of home and community-based services (HCBS), a professional case manager authorizes a care plan and arranges services from approved providers. For some, institutions are the only choice. In recent years, federal policy efforts, including a series of grants to states and two major demonstrations—Cash and Counseling and Money Follows the Person (MFP)—have focused attention on offering Medicaid consumers more choice in arranging supportive long-term care services and helping them transition from institutions to community settings. This Forum session will highlight state efforts to promote consumer-directed long-term care services and state observations about activities under MFP demonstration grants.*

## SESSION

Medicaid beneficiaries who need personal care and other home and community-based services, such as homemaker/chore services or respite care, generally rely on services provided by Medicaid-approved home care agencies, day care programs, and other traditional service providers. The providers employ personal care and other home care workers and determine how and when services will be provided. In recent years, federal and state policymakers have focused on ways to make the long-term care system more responsive to individual preferences by giving consumers more choice and control over their long-term care services, especially in regard to choosing paid helpers and determining how and when their services will be provided. The number of Medicaid beneficiaries directing their own services is relatively small but is growing.<sup>1</sup> Some states have had consumer-directed long-term care programs for many years, and recent federal initiatives have encouraged these programs in other states. Among these initiatives is the Cash and Counseling demonstration, begun in the mid-1990s and funded jointly by the Department of Health and Human Services (DHHS) and the Robert Wood Johnson Foundation. The demonstration tested the effects of a consumer-directed

### National Health Policy Forum

Facilitating dialogue.  
Fostering understanding.

2131 K Street NW, Suite 500  
Washington DC 20037

202/872-1390  
202/862-9837 [fax]  
nhpf@gwu.edu [e-mail]  
www.nhpf.org [web]

### Judith Miller Jones

Director

### Sally Coberly, PhD

Deputy Director

### Monique Martineau

Publications Director

Forum Session Manager

### Carol V. O'Shaughnessy

Principal Policy Analyst

budget for Medicaid beneficiaries receiving personal care and other home and community-based services.<sup>2</sup>

For some elderly and other adults with disabilities who can no longer care for themselves at home, institutions may be the only option. Most enter nursing homes as a result of their care needs, but some do so simply because of the lack of home and community-based services, informal supports, accessible housing, and/or the presence of waiting lists for services. However, evidence suggests that some nursing home residents could live in the community with appropriate supports.<sup>3</sup> The Money Follows the Person (MFP) demonstration aims to help people who are living in institutions transition to community settings and incorporates principles of consumer direction.

### Consumer Direction Initiatives

Consumer-directed services, sometimes referred to as self-direction, evolved as a result of efforts by people with disabilities in the 1970s who wanted to have more control over personal care services that enabled them to live independently in the community.<sup>4</sup> In the broadest terms, consumer-directed long-term care refers to the choices people with disabilities have about hiring, training, scheduling, supervising, and monitoring workers who assist them with activities of daily living. An approach pioneered by the Cash and Counseling demonstration and evaluation (CCDE) goes further; it gives consumers “budget authority” not only to hire their workers, but also to purchase other goods and services of their choosing, such as assistive technologies, home modifications, transportation, and personal care supplies. States have been interested in consumer-directed services for a number of reasons: to respond to consumer demand for more choice, to improve consumer satisfaction and outcomes, and to alleviate worker shortages.<sup>5</sup>

The CCDE was a randomized control trial of consumer direction under Medicaid that attracted a great deal of attention among long-term care policy stakeholders. Beginning in 1998, three states—Arkansas, Florida, and New Jersey—participated in the demonstration. Consumers were randomly assigned to a group who received funds to pay for their services (treatment group) or a group who received agency-provided services. Beneficiaries in the treatment group became, in effect, their own care managers; they controlled their own individualized budgets that they could use to hire personal care workers (including relatives) and purchase other services and supports, such as assistive devices. They also received counseling to assist in their role as “employers” and assistance with fiscal management (help with employment-related paperwork, such as forms required for Social Security and payroll taxes). Results were generally very positive. Both elderly and non-elderly Medicaid recipients who received cash and counseling services were more satisfied, reported fewer unmet needs, and experienced no greater incidence of health or safety problems than those who did not receive these services.<sup>6</sup> Although results on cost savings were

mixed, the evaluation documented decreased use of nursing homes by participants.<sup>7</sup> The federal demonstration has ended, and its results have increased momentum for greater focus on consumer direction by federal and state policymakers.<sup>8</sup>

In addition to the CCDE, a variety of other federal initiatives have encouraged state activity on consumer direction. The Centers for Medicare & Medicaid Services (CMS) has encouraged consumer direction as part of its New Freedom Initiative<sup>9</sup> and through a series of Systems Change grants beginning in 2001.<sup>10</sup> Also, CMS policy now allows states to incorporate consumer direction service options, including budget authority, in their section 1915(c) home and community-based waiver service programs. Finally, a provision in the Deficit Reduction Act (DRA) of 2005 added a Medicaid state plan option for self-direction—section 1915(j)—that allows eligible individuals to have control over funds to purchase personal care services. At state option, individuals may hire legally liable relatives as paid providers.<sup>11</sup>

Despite widespread support for giving consumers more control and choices, some observers have raised a number of concerns. Many consumers who are responsible for paying their personal care workers may feel burdened by doing the necessary employment-related paperwork. State Medicaid agencies may place fiscal limitations on individualized budgets controlled by consumers, and those budgets may be insufficient to meet their needs.<sup>12</sup> Another concern is possible abuse and neglect by providers, especially of consumers with cognitive impairments.<sup>13</sup> Some consumers may face the same challenges regarding recruitment and retention of workers that agencies do, such as high worker turnover. Also, some caution that states setting up these programs should assure that consumers have ongoing support, especially if their service plans prove inadequate (for example, a worker fails to provide needed services or a consumer needs more services than anticipated).<sup>14</sup> Some question whether consumer-directed services will have any long-term impact on nursing home use and cost savings and point to the low enrollment among the elderly in some states.<sup>15</sup> Finally, some worry about quality of care. For example, they fear that workers hired directly by consumers may not receive the same training and supervision as agency-provided workers and that consumers will not receive adequate care. To counteract this concern, some states require that consumer-directed workers receive state-mandated training and point out that long-term care recipients are employers/supervisors and know best what their care needs are.

### **Money Follows the Person Demonstration**

The MFP demonstration, authorized by the DRA of 2005, aims to help people transition from institutions to community settings. MFP provides a source of flexible funding for long-term services and supports that moves with the individual to the most appropriate setting as his or her

needs and preferences change.<sup>16</sup> Congress authorized \$1.75 billion for the MFP demonstration. To date, CMS has awarded 31 grants to states totaling \$1.4 billion over five years. These grants are projected to transition almost 38,000 people from institutions; of these 38,000, about 44 percent are elderly, 26 percent are adults with physical disabilities, 20 percent are people with developmental disabilities, and about 6 percent are people with mental illnesses.<sup>17</sup>

In order to qualify for MFP funds, a person must have resided in a hospital, nursing facility, intermediate care facility for people with mental retardation, or institution for mental disease<sup>18</sup> for a minimum of six months and must need home and community-based services to make a successful transition. In addition, he or she must meet the state's institutional level of care requirement. States participating in the demonstration receive funds for home and community-based services for transitioned individuals at enhanced Medicaid federal matching rates for 12 months after transition.<sup>19</sup> After the 12-month period, states must continue to provide community-based services, through their existing Medicaid programs, for as long as the person needs community services and is Medicaid-eligible. CMS funding preference was given to states that offer consumers the opportunity to direct their community services.

Once transitioned, a person must live in a qualified residence. CMS defines such a residence as a home the person or a family member leases or owns; an apartment with an individual lease, with lockable access and egress, that includes living, sleeping, bathing, and cooking areas over which the individual or the individual's family has domain and control; or a community-based residential setting, where no more than four unrelated individuals reside.

A key issue to be addressed by MFP is the link between services and affordable and accessible housing for low-income people who often have complex health, behavioral, and supportive service needs. Difficulties in finding appropriate housing and services packages for people with disabilities, although recognized by state and community stakeholders for many years, was highlighted most recently by a 2002 congressionally mandated study.<sup>20</sup> MFP funding is intended to help states develop service options for people once they have transitioned into community settings, but the grants will not provide direct funding for housing. Exceptions include one-time costs of furnishing an apartment; security deposits; utility set-up fees; health and safety assurances, such as pest eradication; one-time cleaning prior to occupancy; and home modifications and adaptive equipment/assistive technology to facilitate sustained community living.

Another key issue to be addressed by the demonstration is insufficient incentives in the long-term care system for helping people move from institutions. Social workers and case managers often spend a great deal of time helping people establish eligibility for admission to Medicaid-financed institutions, but rarely are they tasked with helping people move from

institutions. The MFP demonstration supports staff who act as housing “relocation specialists” or “transition coordinators” to assure smooth placement of people into community settings.

## KEY QUESTIONS

- What is the effect of consumer direction and cash and counseling on access to services, consumer satisfaction, supply of service providers, and cost of care for people with disabilities? Who can best benefit from consumer direction? What accounts for the relatively low enrollment of the elderly in some consumer-directed programs?
- How do states assure that consumers receive appropriate, adequate, and quality services? Are these terms defined by consumers or state Medicaid agencies? How do states determine the amount of an individualized consumer-directed budget, and how do they assure that the amount will be sufficient to meet a consumer’s needs?
- How do states help people with cognitive impairments participate in consumer-directed programs?
- What are the major barriers to transitioning people from institutions to community settings? What steps are states taking to assure that MFP clients will be able to successfully direct their own care plans?
- What is the impact of MFP on people with long-term care needs who live in the community and are not eligible for MFP services but are on Medicaid waiting lists for services?
- What initial information is there on the costs of transiting MFP-eligible people to home and community-based services? Given stressed state budgets, will states be able to continue offering MFP services to people who have been transitioned to community settings at the same level as during the demonstration phase, that is, without the enhanced match allowable for the first year?

## SPEAKERS

**Joshua M. Wiener, PhD**, is a senior fellow and program director for aging, disability and long-term care at RTI International. He is the author or editor of eight books and more than 100 articles on health care for older people, people with disabilities, long-term care, Medicaid, health reform, health care rationing, and maternal and child health. He is currently involved in studies of Medicaid home and community-based services, the long-term care workforce, quality assurance for long-term care, and projection and simulation models for long-term care. Dr. Wiener will provide an overview of consumer direction and MFP initiatives, followed by a discussion of selected issues.

**Herb Sanderson** was, until recently, director of the Division on Aging and Adult Services in the Arkansas Department of Human Services, a post he

had held since 1984. He has recently been appointed as the associate state director for advocacy for AARP in Arkansas. He is a past president of the Southwest Society on Aging and was a presidential appointee to the Policy Committee of the 1995 White House Conference on Aging. He serves on the National Academy for State Health Policy Long Term Care Steering Committee. Mr. Sanderson will discuss Arkansas' efforts to implement the national Cash and Counseling and the MFP demonstrations in Arkansas as well as the state's initiatives in consumer direction.

**Marc Gold** is director of the Promoting Independence Initiative, Texas Department of Aging and Disability Services. Mr. Gold has over 23 years of state governmental experience in the field of long-term services and supports. He oversees the Texas response to the 1999 Supreme Court *Olmstead v. L.C.* ruling, including management of the Texas MFP initiative. Mr. Gold holds appointments to the Governor's Commission for Persons with Disabilities and the State Independent Living Council and is vice-chair of the Texas Interagency Homeless Council. He will discuss Texas experience with MFP grants and Texas efforts on consumer direction.

**Maureen Hollowell** is the director of advocacy and services at the Endepence Center, Inc., in Norfolk, Virginia. Ms Hollowell has been involved with policy development and service issues related to consumer-direction since these services were initiated in Virginia. She facilitates the Virginia Medicaid home and community-based services waiver network and manages the Virginia Medicaid waiver technical assistance center. She also serves as a member of the workgroup that developed the Virginia MFP protocol. Ms. Hollowell will discuss consumer direction initiatives for adults with disabilities and recent implementation of the MFP demonstration in Virginia.

---

## ENDNOTES

1. Henry Claypool and Molly O'Malley, *Consumer Direction of Personal Assistance Services in Medicaid: A Review of Four State Programs*, Kaiser Commission on Medicaid and the Uninsured, March 2008; available at [www.kff.org/medicaid/upload/7757.pdf](http://www.kff.org/medicaid/upload/7757.pdf).
2. Robert Wood Johnson Foundation (RWJF), *Choosing Independence: An Overview of the Cash and Counseling Model of Self-Directed Personal Assistance Services*, 2006; available at [www.rwjf.org/files/publications/other/Choosing\\_Independence\\_final\\_nov22.pdf](http://www.rwjf.org/files/publications/other/Choosing_Independence_final_nov22.pdf). In the mid-1990s, RWJF also made grants funds to 18 states for consumer direction initiatives for people with developmental disabilities. See RWJF, "Self-Determination for People with Developmental Disabilities," October 25, 2007; available at [www.rwjf.org/pr/product.jsp?id=17885](http://www.rwjf.org/pr/product.jsp?id=17885).
3. Vincent Mor *et al.*, "Prospects for Transferring Nursing Home Residents to the Community," *Health Affairs*, 26, no. 6, (November/December 2007): pp. 1762-1771; available at <http://content.healthaffairs.org/cgi/reprint/26/6/1762?>
4. Lori Simon-Rusinowitz and Brian F. Hofland, "Adopting a Disability Approach to Home Care Services for Older Adults," *Gerontologist*, 33, no. 2 (April 1993): pp. 159-167.

Endnotes / continued ►

**Endnotes / continued**

5. Janet O’Keefe, Joshua Wiener, and Angela Greene, *Consumer Direction Initiatives of the FY 2001 and 2002 Grantees; Progress and Challenges*, RTI International, prepared for the Centers for Medicare & Medicaid Services (CMS), September 2005; available at [www.hcbs.org/files/93/4603/ConsumerDirInit.pdf](http://www.hcbs.org/files/93/4603/ConsumerDirInit.pdf). See also Joshua M. Wiener, Wayne L. Anderson, and Galina Khatutsky, “Are Consumer-Directed Home Care Beneficiaries Satisfied? Evidence from Washington State,” *Gerontologist*, 47, no. 6 (December 2007): pp. 763–774.
6. Barbara Lepidus Carlson *et al.*, *Effect of Consumer Direction on Adults’ Personal Care and Well-Being in Arkansas, New Jersey, and Florida*, executive summary, Mathematica Policy Research Inc., prepared for the Department of Health and Human Services (DHHS), May 16, 2005; available at <http://aspe.hhs.gov/daltcp/reports/adultpcw.htm#execsum>.
7. Medicaid costs for the treatment group were initially higher because people in the control group served in the agency-based model did not get the full services that were authorized for them. Stacey B. Dale and Randall S. Brown, “How Does Cash and Counseling Affect Costs?” *Health Services Research*, 42, supp. 1 (February 2007): pp. 760–767; available at [http://findarticles.com/p/articles/mi\\_m4149/is\\_jai\\_n27150806](http://findarticles.com/p/articles/mi_m4149/is_jai_n27150806). See also Stacey B. Dale and Randall S. Brown, “Reducing Nursing Home Use Through Consumer-Directed Personal Care Services,” *Medical Care*, 44, no. 8 (August 2006): pp. 760–767; Stacey Dale *et al.*, “The Effects of Cash and Counseling on Personal Care Service and Medicaid Costs in Arkansas,” *Health Affairs Web Exclusive* (November 19, 2003): pp. W3-566–W3.575, available at <http://content.healthaffairs.org/cgi/reprint/hlthaff.w3.566v1>.
8. In 2004, RWJF, the Retirement Research Foundation, and federal government agencies gave grants and technical assistance to 12 states to replicate “cash and counseling” programs. Although a few states have adopted similar programs without grant funding, many others have done so with the assistance of Medicaid section 1115 waivers and/or Systems Change grants from CMS and, since 2007, from Administration on Aging–funded nursing home diversion grants. For more information, see the Cash and Counseling Web site at [www.cashandcounseling.org/](http://www.cashandcounseling.org/).
9. The New Freedom Initiative, announced by President Bush on February 1, 2001, is a nationwide effort to remove barriers to community living for people with disabilities. As part of the initiative, CMS developed Independence Plus templates that allowed states to choose various self-directed models. A section 1115 demonstration template was developed for states that wanted to permit individuals to receive cash allowances equivalent to the amount of their Medicaid personal care benefits. Another template was developed for states wishing to offer consumer direction under section 1915 (c) waivers, but without a cash allowance. *Federal Register*, 73, no. 193 (October 3, 2008): pp. 57853–57886; available at [http://federalregister.gov/OFRUpload/OFRData/2008-23102\\_PL.pdf](http://federalregister.gov/OFRUpload/OFRData/2008-23102_PL.pdf).
10. Cynthia Shirk, “Trading Places; Real Choice Systems Change Grants and the Movement to Community-Based Long-Term Care Supports,” National Health Policy Forum, Issue Brief 822, May 30, 2007; available at [www.nhpf.org/pdfs\\_ib/IB822\\_SystemsChange\\_05-30-07.pdf](http://www.nhpf.org/pdfs_ib/IB822_SystemsChange_05-30-07.pdf).
11. *Federal Register*, October 3, 2008.
12. O’Keefe, Wiener, and Greene, *Consumer Direction Initiatives*. See also Brenda C. Spillman, Kirsten J. Black, and Barbara A. Ormond, *Beyond Cash and Counseling: The Second Generation of Individual Budget-Based Community Long-Term Care Programs for the Elderly*, Kaiser Commission on Medicaid and the Uninsured, January 2007; available at [www.kff.org/medicaid/upload/7579.pdf](http://www.kff.org/medicaid/upload/7579.pdf).
13. Jane Tilly, “Consumer-Directed, Home and Community Services for Adults with Dementia,” Alzheimer’s Association, Public Policy Issue Brief, July 2007; available at [www.alz.org/documents/advocacy\\_public\\_policy\\_issue\\_brief\\_71107.pdf](http://www.alz.org/documents/advocacy_public_policy_issue_brief_71107.pdf).
14. Claypool and Malley, *Consumer Direction of Personal Assistance Services*.
15. Spillman, Black, and Ormond, *Beyond Cash and Counseling*.

**Endnotes / continued ►**

**Endnotes / continued**

16. CMS, "Money Follows the Person Rebalancing Demonstration," Funding Opportunity No. HHS-2007-CMS-RCMFTP-0003, DHHS, July 26, 2006; available at [www.cms.hhs.gov/NewFreedomInitiative/downloads/MFP\\_2007\\_Announcement.pdf](http://www.cms.hhs.gov/NewFreedomInitiative/downloads/MFP_2007_Announcement.pdf).

17. Carey Appold, CMS, "Money Follows the Person," presentation to National Association of State Agencies Units on Aging, June 24, 2008.

18. People residing in an institution for mental diseases may be eligible only if a state covers these institutions as part of its Medicaid plan.

19. The enhanced federal medical assistance percentage (FMAP) that each state receives is equal to its standard federal match plus the number of percentage points that is 50 percent of the regular state share. Therefore, if a state's regular matching rate is 50 percent, the enhanced demonstration FMAP equals 50 percent plus one-half of 50 percent, for a total of 75 percent. If a state's regular matching rate is 30 percent, the enhanced demonstration FMAP equals 70 percent plus one-half of 30 percent, or 85 percent. In no case can the enhanced matching rate exceed 90 percent.

20. Commission on Affordable Housing and Health Facility Needs for Seniors in the 21<sup>st</sup> Century, *A Quiet Crisis in America*, report to Congress, June 30, 2002; available at [http://govinfo.library.unt.edu/seniorscommission/pages/final\\_report/finalreport.pdf](http://govinfo.library.unt.edu/seniorscommission/pages/final_report/finalreport.pdf).



*The National Health Policy Forum is a nonpartisan research and public policy organization at The George Washington University. All of its publications since 1998 are available online at [www.nhpf.org](http://www.nhpf.org).*