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Consumer Direction in Medicaid and Opportunities for States

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The Center for Medicare and Medicaid Services (CMS) published a final Medicaid rule that permits Medicaid recipients to self-direct their own health care and supportive services. The rule, *Self-Directed Personal Assistance Services Program State Plan Option (Cash and Counseling)*, is a great victory for persons with disabilities. Medicaid recipients in need of long-term care have been given the freedom to control their own destiny. If states take advantage of it, this change has the potential to revolutionize the $100 billion long-term care delivery system under Medicaid.

Medicaid Dominance in Long-Term Care. The Medicaid program is the largest single source of funding for long-term care, accounting for nearly half of paid caregiving. Approximately one-third of Medicaid spending goes to long-term care ($114 billion in FY 2009). Over the next 10 years, Medicaid is projected to spend $1.7 trillion on long-term care.[1]

Provider special interests benefit from the status quo. Most Medicaid spending on long-term care is still provided in nursing homes, institutions for mental diseases, and intermediate care facilities for persons with mental retardation or developmental disabilities. Large public and private institutions are also often staffed by health care workers represented by unions.

People need long-term care services because they have limitations in their functional ability to meet their own needs in the "activities of daily living" such as bathing, dressing, cooking, and eating. Individuals may need assistance due to an array of conditions including developmental disabilities (autism, mental retardation), chronic mental illness, other severe cognitive impairment, or physical disabilities. As part of a defined benefit program, a person on Medicaid is entitled to coverage in a nursing home as a mandatory service. Individuals often do not have a choice about long-term care; placements are made by default as to what is available.

Self-direction, with the benefit of counseling, is a dramatic reversal of the traditional model of long-term care that is based on dependency. Self-direction puts the individual back in control. This raises expectations and demands greater personal responsibility on the part of the Medicaid recipient. But properly understood, that in itself adds value and quality as well as expands access to services.

Early Alternatives and New Options. In the early 1980s, home- and community-based services were allowed as an alternative to institutional care. States gradually developed their waivers and expanded the number of people served by them. Typically, states would contract with local government or private agencies to provide direct services. But control over hiring, what services were provided, how many units of services were allowed, and when

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services were provided was generally in the hands of the state, local government, or agency.

In contrast, self-direction is a person-centered, market-based approach founded on the belief that individuals themselves know best as to what they (or a family member) need to support themselves in their own homes. Individuals may manage a service budget and directly purchase goods and services using a cash allowance or may direct a service plan in which a separate entity makes the actual procurement of services. Self-direction generally includes at least personal care services but may also include a broader array of goods and services including transportation and supportive employment.

John Kemp, an expert on disability issues, has explained that "control and choice is not just a theme; they are a tenet of the disability movement."[2] Experience shows, moreover, that putting the consumer rather than the provider in control is also cost effective as well as personally liberating. Says Kemp: "We have been trying to save our government money for a long time."[3]

Promoting Dignity. "Cash and Counseling" in Medicaid was a seed planted in the mid-1990s through grants from the Robert Wood Johnson Foundation. Arkansas, Florida, and New Jersey became the leaders of self-direction programs and demonstrated what such independence can mean to people on Medicaid. In his first month in office, President George W. Bush issued his New Freedom Initiative and challenged federal officials to promote "full access to community life" for disabled persons. Consequently, the U.S. Department of Health and Human Services (HHS) developed *Independence Plus*, a Medicaid model waiver for the states that incorporated self-direction. It was ultimately adopted by 15 states. Waivers are, however, discretionary and temporary. The Deficit Reduction Act of 2005 gave authority to the states to offer it as a state plan option. Self-direction is federal policy; it must be carried out, however, at the state and local levels.

Personal Benefits. Suzanne Crisp, another expert on the policy of self-direction, spells out its numerous benefits:

- Higher levels of consumer satisfaction;
- Fewer unmet patient needs;
- The same or better scores on measures of health status;
- The same or better scores on measures of participant safety;
- Reported better quality of life;
- No experience of adverse effects on health; and
- An expanded labor market for a non-traditional pool of workers.[4]

Crisp notes there are tremendous opportunities to expand these benefits, as there are "almost 2 million Americans who receive publicly funded personal care services each year."[5]

In a study of individuals with mental illness who self-direct part of their own care, Vidhya Alakeson, an HHS official, found that "the traditional system was seen by consumers to be unsupportive and consumers felt uninformed about their diagnosis and medications."[6] Alakeson also noted that "consumers expressed the view that the public mental health system focused too heavily on illness and did not foster wellness. They valued the fact that SDC [self-directed care] was explicitly focused on creating or sustaining a life in the community and on the full range of their needs."[7]

1. Office of the Actuary, Centers for Medicare and Medicaid Services, State Health Reform: Converting Medicaid Dollars into Premium Assistance, table A2, September 16, 2008.
2. John Kemp, "Workable Solutions for Long-Term Care," lecture at The Heritage Foundation, September 24, 2008.
3. *Ibid.*
4. Suzanne Crisp, "Self-Direction: An Innovative Design for Systems Change," lecture at The Heritage Foundation, September 24, 2008.
5. *Ibid.*
6. Vidhya Alakeson, "The Contribution of Self-Direction to Improving the Quality of Mental Health Services," U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, November 2007, p. 29, at *http://www.aspe.hhs.gov/daltcp/reports/2007/MHslfdir.pdf* (November 12, 2008).

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Some have opposed various state efforts to introduce greater personal responsibility in the Medicaid program with the rationale that the lives of Medicaid families are too chaotic to expect compliance or involvement. But as Alakeson has found, that is precisely what some of the most vulnerable Medicaid recipients themselves want. Self-direction has positive effects beyond health status. Prior to the start-up of self-direction in Florida, only 23 percent of participants were employed, and just 8 percent were in school. By the end of the first year of self-direction, 47 percent of participants were working and 44 percent were being educated.[8]

Taxpayer Savings. Savings from successful self-direction will show up across the board in public programs. With competition from self-direction, the following will occur:

- Traditional personal care agencies will improve quality;
- Participants will trade welfare checks for paychecks;
- Individuals will leave group homes (more expensive) for their own homes (less expensive);
- Vacancies in group homes will mean states will have available capacity to move more individuals from the state institutions (more expensive) to group homes (less expensive); and
- Stabilization and recovery will reduce acute care services in emergency rooms and inpatient hospitalization.

In addition, there are significant costs associated with serving people with mental illness through the judicial system. Such costs are typically borne by state and local governments, so improvement in the service delivery system brought by self-direction will provide savings to them.

Opportunities for the States. The change in federal law is now complete. Because the new regulation is final, it is time for the states to act and adopt self-direction as part of overall Medicaid reform. States can adopt self-direction through a simple state plan amendment process. All that is needed is a change in philosophy and a change in attitudes in the state capitals and among local public officials toward people with disabilities. Medicaid recipients and taxpayers alike will benefit.

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7. *Ibid.*, p. 22.
8. *Ibid.*, p. 25.