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News Release

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MEDICAID RECIPIENTS WITH DISABILITIES BENEFIT FROM DIRECTING THEIR OWN PERSONAL CARE SERVICES, STUDY FINDS

Medicaid recipients with disabilities who direct their own supportive services were significantly more satisfied and appeared to get better care than those receiving services through home care agencies, according to initial findings of a demonstration project jointly supported by HHS and the Robert Wood Johnson Foundation. With self-direction, the recipients' satisfaction and quality of life were improved substantially and unmet needs for care were reduced, without compromising health or safety, the study found.

The initial findings, from an ongoing evaluation of the Cash and Counseling demonstration project, were released in a web exclusive edition of the journal *Health Affairs*. In the project, participants are given an allowance and a high degree of flexibility and freedom to choose personal care assistants. The first phase of the evaluation examined whether this self-directed care succeeded at protecting recipients' health and safety in addition to enhancing their satisfaction. The study looked at both elderly and non-elderly adult Medicaid recipients with disabilities who receive Medicaid-supported home services.

"This approach gives people with disabilities more freedom and responsibility, in the same way that all of us want to be in charge of our lives and our choices," said HHS Secretary Tommy G. Thompson. "It lets the individuals themselves decide how best to use the Medicaid dollars they are already entitled to. The study confirms that these Medicaid recipients make good choices that maintain their health and safety, even as they improve their convenience, satisfaction and quality of life."

"The Cash and Counseling program offers Medicaid consumers flexibility and a sense of control over their care," said Risa Lavizzo-Mourey, M.D., M.B.A., president and CEO of the Robert Wood Johnson Foundation. "We're encouraged that these initial findings indicate that giving patients this kind of greater autonomy over their choices for care can enhance the quality of their lives. This program is an important part of the Robert Wood Johnson Foundation's longstanding mission to improve the quality of care for people with chronic conditions."

The Cash and Counseling demonstration project is being tried in Arkansas, New Jersey and Florida. The study announced today contains findings from the Arkansas demonstration, which was the first to be implemented. The demonstration examines delivery of personal care services like bathing, grooming and meal preparation. Most states provide some coverage for such services in their Medicaid programs, in part to help maintain individuals in their homes rather than in nursing facilities or other institutional settings. In most cases, these supportive services are provided by home care agencies.

The Cash and Counseling Demonstration was designed to compare outcomes of traditional agency-directed care with care that is directed by the recipient -- especially to determine whether satisfaction increased and health and safety were maintained. Under the Cash and Counseling approach, the recipient (or designee) is provided with a monthly allowance, equivalent to what would be spent under traditional Medicaid for the care authorized, and a high degree of freedom in using the allowance. For example, recipients may use their allowances to hire friends and family members (excluding spouses) as caregivers. They may also use the monthly allowance to purchase assistive

equipment or home-modifications related to their personal care needs. Counseling is provided to help recipients develop a spending plan for the allowance..

Medicaid beneficiaries who receive supportive services from agencies "often have little control over who provides their care, when they receive it, or how it is delivered. For some, this lack of control over basic, often intimate, assistance leads to dissatisfaction, unmet needs and diminished quality of life," says the report. At the same time, the report notes, "some stakeholders fear that eliminating agency involvement jeopardizes consumer health and safety."

The study announced today compared randomly selected, voluntary participants using the Cash and Counseling approach with a control group of those who had to rely on traditional agencies. Findings include:

- Satisfaction with caregivers was much higher for those in Cash and Counseling. Reports of paid caregivers failing to complete tasks were about 60 percent lower than the control group.
- The Cash and Counseling group was much less likely to report unmet needs for assistance of several types. For example, the proportion of non-elderly consumers not receiving desired help with transportation was about 40 percent lower than for the control group rate.
- Care for those in the Cash and Counseling approach was at least as safe as agency-directed care, as reflected in reports of disability-related adverse events, health problems and general health status.
- Program participants were nearly 20 percentage points more likely than the control group to express satisfaction with their lives, among both elderly and non-elderly consumers.

"States are increasingly interested in using consumer-directed approaches for this kind of supportive care," said Kevin Mahoney, director of the demonstration's national project office at the University of Maryland Center on Aging, which oversees the project. "But before expanding these programs, the states want to be sure this approach is safe as well as satisfying for patients. The Cash and Counseling Demonstration is answering those questions."

Future reports will deal with other aspects of the Arkansas program, as well as the demonstrations in New Jersey and Florida. Altogether, some 1.2 million Medicaid recipients nationwide get supportive services.

"Approaches like this hold great promise for making Medicaid more cost-effective and serving people with disabilities better," said Tom Scully, administrator of HHS' Centers for Medicare and Medicaid Services (CMS). "These approaches are especially important in light of the President's New Freedom Initiative, in which he has directed government to do more to help people with disabilities to live at home and avoid institutionalization."

Recent actions by HHS have made it easier for states to adopt consumer-directed approaches for Medicaid recipients with disabilities. "Independence Plus" waiver templates, introduced by HHS last year, enable states to obtain the needed permission to operate such programs with a minimum of HHS review. Funds provided under the Real Choice Systems grants also help support states in planning such programs.

In addition, President Bush has proposed changes in the Medicaid program that would give states much more flexibility. Under the proposal, states would be able to implement programs of this kind without needing to obtain HHS permission.

The Cash and Counseling programs in each of the three states are funded by the Robert Wood Johnson Foundation. The evaluation is funded jointly by the foundation and HHS Office of Planning and Evaluation.

Today's study, carried out by Mathematica Policy Research, Princeton, N.J., is available at: <http://content.healthaffairs.org/cgi/content/abstract/hlthaff.w3.162v1>.

More information on the Cash and Counseling demonstration program is available at www.umd.edu/aging.

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