



## Pennsylvania Confronts Challenges to Create Stronger Self-Directed Personal Assistance Services

The state of Pennsylvania has allowed Medicaid recipients with physical disabilities to make decisions about their personal assistance services since 1984. This included allowing them to hire, manage, pay, and fire workers. Since then, Pennsylvania has added options for self-directed personal assistance services through eight 1915(c) home and community-based services waiver programs, including the aging and attendant care waivers. Waivers granted by the Centers for Medicare & Medicaid Services let states test ways to deliver and pay for health care services in Medicaid.

These self-directed programs let participants choose and hire workers but did not give them control over the services they received or let them buy things to support their independent living. Also, not all programs were available statewide.

With a \$249,995 grant from the *Cash & Counseling* national program,<sup>1</sup> Pennsylvania had planned to develop and implement a cash and counseling program, called Services My Way, in its aging waiver program statewide and in six other waiver programs in some counties. Pennsylvania was one of 15 states that introduced or expanded participant-directed personal assistance services into their Medicaid programs through the *Cash & Counseling* program between October 1996 and March 2009.

The Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation in the U.S. Department of Health and Human Services co-sponsored *Cash & Counseling*. See [Program Results Report](#) for more information about *Cash & Counseling*.

People who opt to participate in cash and counseling, or participant-directed, programs prepare a written plan for permissible goods and services that best meet their functional assistance needs and manage a budget (equal to what traditional providers would have received for services) to pay for goods and services. They hire and pay the workers they choose, who can be family members or friends, to provide those services. They can use

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<sup>1</sup> Grant ID # 52100 from October 2004 to February 2009

their budget to buy goods such as a microwave to heat up meals and to modify their homes or vehicles to help them live independently.

Participants get counseling to help them make decisions about and manage their services and help with the paperwork required to pay an employee's wages and withhold taxes. They can also appoint a representative to make decisions with or for them.

## **CHALLENGES IN DEVELOPING AND IMPLEMENTING SERVICES MY WAY**

From the start, Pennsylvania experienced many significant challenges with Services My Way. In the end, the state was able to offer the program only to Medicaid beneficiaries who were eligible for the aging and the attendant care waivers—people over the age of 60 and people ages 18 to 59 with physical disabilities who met the level of care needed for placement in a nursing home or a special rehabilitation facility, respectively.

Strife within the state government and lack of previous oversight of financial management services were key challenges for Pennsylvania. The Governor's Office of Health Care Reform, established in 2003 to improve health and long-term living services in Pennsylvania, submitted the proposal and was managing the grant. But the office had no authority over the agencies that operated the waiver programs related to Services My Way, and these agencies were suspicious of—and resistant to—initiatives coming out of the Governor's Office of Health Care Reform.

“They could not come to a consensus on what they wanted the program to look like,” said Virginia Brown, the original project manager for the grant in the Governor's Office of Health Care Reform (as of December 2012, Brown was director of the Bureau of Individual Support in the Department of Public Welfare's Office of Long-Term Living).

Lack of consensus delayed the work and left the state unable to prepare the necessary waivers to implement Services My Way for adults with physical disabilities and developmental disabilities. After a period during which waivers were submitted and then withdrawn, the state was only able to amend the aging and attendant care waivers to do a pilot demonstration in 21 counties.

Since Pennsylvania had a history of offering self-directed services and comprehensive benefits to Medicaid recipients covered by the aging and attendant care waivers, Services My Way held limited appeal to key stakeholders: potential participants, state staff, and the personal assistance workers and staff from area agencies on the aging who were already working with participants in the existing self-directed programs. The area agencies on aging in Pennsylvania provide services that help older adults remain in their homes, including counseling people who are interested in self-directed programs.

Potential participants were afraid Services My Way would negatively affect their ability to hire workers. State and other staff did not understand the idea of giving participants a budget to manage, and there were inconsistencies among agencies in the ways staff understood their roles in self-directed programs, with some traditionally taking a very hands-off approach. To increase buy-in, project staff met with other state staff, potential participants, and staff from provider organizations and the area agencies on aging to explain the program. They also made presentations, conducted focus groups, created an advisory committee composed of stakeholders, established several workgroups, and provided training to state staff.

The biggest challenge related to the financial management services component of the program. The state required the agencies that were providing home care services under seven waiver programs to also provide financial management services such as disbursing funds, withholding and filing taxes, and processing time sheets. But the state had been providing little oversight of the financial management services entities and had little understanding of how they operated. The state agencies responsible for the waiver programs did not assess or monitor the financial management services and had different expectations for the providers and different policies for reimbursing them.

There was also an inherent conflict of interest in expecting the agency that provided home care services to also help people hire and supervise their workers. “It all boiled down to having the conflict of interest of having the financial management being provided by the service agency because they would self refer,” said Brown. This resulted in few people being told about Services My Way.

Brown and other project staff began looking at better options for financial management services. After working with an expert from the *Cash & Counseling* national program office, they met with a group of stakeholders and put together standards, implemented in December 2008, for financial management services entities.

## **LAUNCHING SERVICES MY WAY**

The pilot Services My Way program for Medicaid recipients covered by the aging and attendant care waivers started in July 2009 in 21 counties. Pennsylvania had enrolled only two participants as of September 30, 2009. Services My Way became available statewide in July 2011, after the state amended the aging and attendant care waivers to expand the program statewide. As of December 2012, about 75 Medicaid beneficiaries were enrolled in Services My Way through the aging and attendant care waivers.

Services My Way gives participants a flexible budget within which they can design a service plan and choose the goods and services they need to continue living at home. It gives people who are already self-directing their services more choices than they had before, such as deciding how much to pay workers and when to give them a raise, and

buying things that are not allowed through other programs. Participants can hire a friend, neighbor, or other trusted person (including a family member but not the spouse) as their worker.

A service coordinator from a local area agency on aging helps participants develop and implement their plan. The fiscal management services providers from other self-directed programs help them with the paperwork required to pay an employee's wages and withhold taxes and with receiving and disbursing program funds.

## **ADDRESSING THE CHALLENGES: CREATING STRONGER SELF-DIRECTED SERVICES**

Despite the many challenges Pennsylvania faced during its participation in the *Cash & Counseling* program, the state is moving toward stronger self-directed services. Identifying and correcting the issues with the financial management services was key.

Along with establishing the standards for financial management services providers, in December 2012, Pennsylvania transitioned to a single provider for these services. "We're truly hoping that with this move to a statewide vendor of financial management services we will finally have some legitimacy to the program, that people will be offered the choice of budget authority because there will no longer be the conflict," said Brown.

The work done to develop Services My Way and participate in *Cash & Counseling* also helped state staff, providers, and participants better understand the role of giving people the authority to determine their own priorities for allocating their budget.

"We would also like to see the model grow, and see about expanding it into some of our other waiver programs," said Brown. The state plans to collect data on participants in Services My Way for use in decisions about expanding the model.

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### **Prepared by: Lori De Milto**

Reviewed by: Mary Nakashian and Molly McKaughan

Program Officers: Nancy Wieler Fishman and James Knickman

Program area: Vulnerable Populations

Grant ID# 52100

Project Director: Virginia Davies Brown (717) 783-4510; virbrown@pa.gov

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