



self-directed care

This is the third of a six-part series concerning the implementation of Senate Enrolled Act 493, a law passed by the Indiana General Assembly in 2003 to expand the availability of home health care in Indiana. Under SEA 493, the state is required to provide access to self-directed care services that are appropriate and needed for eligible individuals. Importantly, SEA 493 required Indiana to have self-directed care options and services available to individuals receiving services under Indiana's CHOICE program and services through a Medicaid waiver by July 1, 2004.

In spite of these requirements, individuals receiving Medicaid home care services who wish to self-direct their care continue to be denied this option. Part 3 of The Moving Forward Series defines self-directed care, explores options Indiana can take in implementing self-directed care for home care recipients, and makes the case as to why Indiana must implement this service delivery model.

According to ***Moving Forward***, Self-directed care (also known as consumer-directed care) is a service delivery model that gives consumers and/or their families the right and the authority to develop service and support plans that reflect their wishes and preferences and to choose some or all of the following: who will provide their care; training, hiring, and firing of the person selected; service scheduling; purchasing and supervising the service; and possibly directing the payment of personal assistance and other support providers.

The concept of self-direction grew out of the independent living movement during the 1960s and 1970s and has been incorporated in state Medicaid Programs for more than 20 years. One of the largest consumer-directed Medicaid programs in the country is in California, where the program serves around 200,000 annually, 135,000 of which are Medicaid-funded.¹

Self-directed care is a critical element for Indiana's long-term care service delivery system for three main reasons: (1) because it affords low-income elderly and disabled individuals more control and choice in how and by whom they receive personal care and assistance; (2) because it provides a new recruitment opportunity to grow an otherwise limited pool of low-wage workers; and (3) because it provides additional quality assurance opportunities. Through a self-directed care model, consumers are encouraged to network within their own community to identify family members, friends, fellow churchgoers, or others who may be able and willing to provide them with the personal care that they need to remain safe and independent in the community. It may serve to formalize a care relationship that already exists, to replace a previous personal care arrangement that was not reliable or otherwise satisfactory, or to establish a new relationship where previously there was none.

Al Tolbert, Director of the Southern Indiana Center for Independent Living, feels very strongly that self-directed care is about freedom. "It's about the freedom to take care of your personal needs, freedom to take a bath when it is needed, freedom to go to bed at time of your choice, freedom to control your life, freedom to maintain self respect, freedom to improve your health, freedom to have a life, freedom to be like other individuals who don't have disabilities," said Tolbert.

Although there are many variations in how self-directed care is administered, there are three general service delivery models that states typically follow in establishing a self-directed care program.

- *Direct Pay Model.* A service model whereby the consumer assumes responsibility for all functions. The consumer is the employer of record and handles hiring, firing, training, supervising, and scheduling, and assumes payroll and tax responsibilities. The State of Kansas uses a variation of this model.
- *Fiscal Intermediary Model.* A service model whereby personal care workers are selected, hired, and trained by the consumer, but responsibility for wages, payroll taxes, and worker's compensation insurance are assigned to a state agency or a third-party fiscal intermediary with whom the state contracts. The State of Florida uses a variation of this model through one of the Cash and Counseling Demonstration grants.
- *Cash and Counseling.* A service model whereby personal care workers are selected, hired, trained, and paid for by the consumer with monthly cash payments deposited electronically into participants' bank accounts. A fiscal intermediary is available but not required. Several states use this model through one of the Federal Independent Choices research and demonstration waiver initiatives.

According to *Moving Forward*, implementation of a self-directed care initiative within the Indiana Medicaid Waiver Programs can be expected to accomplish a number of long-term care rebalancing objectives. Specifically, a successful self-directed care program can be expected to grow the pool of personal care workers, improve employment retention rates for persons already serving as personal care workers, reduce unnecessary institutionalizations, and most importantly, improve consumer health outcomes and quality of life. According to Nancy Griffin, AARP Indiana state director, "When people are given the choice of who they hire to deliver the care they need, they definitely report higher levels of satisfaction with their services. In fact, studies have shown that when given control over how to spend their long term care dollars, consumers and families can often arrange to obtain more services than when their care is managed by others." Finally, implementation of a self-directed care program helps to satisfy some of the State's objectives in meeting the requirements established by the U.S. Supreme Court for publicly funded home and community based services in its Olmstead decision.

The U.S. Department of Health and Human Services and the Robert Wood Johnson Foundation supported Mathematica Policy Research, Inc. in conducting an evaluation of the Arkansas Cash and Counseling Demonstration and Evaluation. Findings from that evaluation revealed that the vast majority of Medicaid enrollees who were given the opportunity to direct their own personal care services using a cash allowance hired a family member or friend to perform the services and indicated a higher quality of life, greatly-improved satisfaction, were more likely to get the services for which they were entitled, and were able to receive significantly more personal care services at no greater net costs to the Medicaid Program.ⁱⁱ

Indiana currently offers self-directed care on a limited basis through its state-funded CHOICE program. It is administered through the sixteen area agencies on aging and serves approximately 100 elderly and disabled individuals. For information on the utilization of self directed care by individuals in your area, please contact your local area agency on aging or a local Center for Independent Living. For area contacts, please visit www.iaaaa.org/members/aalist.asp or www.in.gov/fssa/servicedisabl/vr/ilcenters.html.

The full *Moving Forward Report* is available at www.generationsproject.org

ⁱ "Understanding Medicaid Home and Community Services: A Primer", U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, October 2000, p. 118.

ⁱⁱ "Improving the Quality of Medicaid Personal Assistance Through Consumer Direction", Leslie Foster, Randall Brown, Barbara Phillips, Jennifer Schore, Barbara Lepidus Carlson, Health Affairs, 26 March 2003, pp. 170-171.