

IN-BRIEF**Consumer-Directed Personal Care Services for Older People
in the U.S.****Introduction and Background**

Retaining independence and control over one's life is a major concern for people of all ages with disabilities. That desire for control and choices may be limited, however, for people with disabilities who receive publicly funded home care services provided by agencies that determine the type of services the consumer receives, select a worker for the consumer, and arrange a schedule for delivery of services.

A newer service model, known as "consumer direction" (CD), has been adopted by many publicly funded home and community-based programs in recent years. Consumers assess their own needs and determine how and by whom those needs should be met. Championed at first by the disability rights and independent living movement for younger adults with disabilities, the concept of self determination and choice has increasingly been embraced by states for different populations including older people, other adults with physical disabilities, and even persons with cognitive disabilities.

Despite the concerns of some administrators and policy makers that many older persons may be too sick or frail to direct their own care, several states have operated CD programs for more than 20 years that include a significant number of older persons. These programs have not reported major problems for this population. To the contrary, several major evaluations of recent CD programs have concluded that the older participants were highly satisfied with such programs and reported greatly improved satisfaction with services.

This *In-Brief* summarizes the CD programs in four states (Colorado, Michigan, Oregon, and California) and one cross-state demonstration program (Cash-and-Counseling Medicaid demonstration program in Arkansas, New Jersey, and Florida) that are described in greater detail in the AARP Public Policy Institute Issue Brief, *Consumer-Directed Personal Care Services for Older People in the U.S.* (IB Number 64).

State CD Programs

An October 2001 study identified a total of 139 CD programs in every state except Tennessee. Almost half a million people were participating in those programs, with 73 percent of the programs serving adults aged 18 to 64 with physical disabilities, and 51 percent serving older persons age 65 and older. Sixty-five percent of the programs relied in whole or in part on Medicaid funding, with the others funded by state general revenues or the federal Social Services Block Grant program.

CD programs in Colorado, Oregon, Michigan, and California have long histories dating back to the late 1970s and early 1980s, but differ considerably in their structure, funding sources, and average monthly benefits. For example, the state-funded *Colorado Home Care Allowance* provides modest monthly allotments of \$86 to \$269 (in 2003) while a participant in the Medicaid-funded program *Oregon Client-Employed Provider Program* could receive up to \$1,950 a month for in-home services in FY 2002.

These two programs and *Michigan Home Help* and the *California In-Home Supportive Services* programs are similar, however, in having a sizeable number of older participants (age 65 and older), and in allowing participants to hire family members to be their workers. An evaluation study of the California program found that a little more than half of the persons age 65 and older in the study sample who were using a consumer-directed model hired family members to provide their services.

In the Cash-and-Counseling demonstration states, participants were randomly assigned to a consumer-directed or agency model. In the CD program, monthly cash allowances allowed participants to hire their own workers, including family and friends, and to purchase assistive equipment, personal care supplies, and medications. In analyzing the Arkansas program, researchers concluded that older people in the CD model were more satisfied with their personal care and with how they were spending their lives than were those who relied on agency services.

Policy Implications

Although many studies and recent state experiences with CD programs that have included older people have reported a high level of satisfaction with this model, older consumers differ in the extent of control they want to exercise over their services and workers. States could provide a range of options for consumers who want to direct their care, but not manage all administrative or fiscal tasks. States can also develop and offer counseling services and training programs for consumers and workers. Emergency procedures and funds can be made available to allow consumers to return to traditional services if they find they cannot or no longer want to manage their own care.

Policy makers need to develop a range of CD models with flexible options and considerable support for the participants and their families. With the right options and supports, consumer direction can represent a large step forward in meeting the needs of people with disabilities in a way that respects their individual preferences and circumstances.