



U.S. Department of Health and Human Services  
Assistant Secretary for Planning and Evaluation  
Office of Disability, Aging and Long-Term Care Policy



# **HIGHLIGHTS:**

## **INVENTORY OF CONSUMER-DIRECTED SUPPORT PROGRAMS**

2002

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This report was prepared under contract #HCFA-99-039/FB between HHS's ASPE/DALTCP and the MEDSTAT Group. Additional funding was provided by the HHS Centers for Medicare and Medicaid Services. For additional information about this subject, you can visit the DALTCP home page at [http://aspe.hhs.gov/\\_/office\\_specific/daltcp.cfm](http://aspe.hhs.gov/_/office_specific/daltcp.cfm) or contact the ASPE Project Officer, Pamela Doty, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. Her e-mail address is: [Pamela.Doty@hhs.gov](mailto:Pamela.Doty@hhs.gov).

# **HIGHLIGHTS:**

## **Inventory of Consumer-Directed Support Programs**

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2002

Prepared for  
Office of Disability, Aging and Long-Term Care Policy  
Office of the Assistant Secretary for Planning and Evaluation  
U.S. Department of Health and Human Services  
Contract #HCFA-99-039/FB

The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of the Department of Health and Human Services, the contractor or any other funding organization.

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"Consumer-direction" is a philosophy and orientation to the delivery of home and community-based long-term care that puts informed consumers and their families in the driver's seat with respect to making choices about how best to meet their disability-related supportive service needs. At a minimum, the consumer-directed services model allows persons with disabilities of all ages or others, such as family members, acting as their representatives to select and dismiss the individuals -- generally termed personal assistants, aides, or attendants -- who are paid to provide assistance with basic and instrumental activities of daily living and other disability-related supportive services. In June 2001, the Home and Community-Based Resource Network at Boston College, with support from the U.S. Department of Health and Human Services (the Office of the Assistant Secretary for Planning and Evaluation and the Centers for Medicare and Medicaid Services) contracted with EP&P Consulting to develop a descriptive inventory of publicly-funded programs offering home and community-based personal assistance services through consumer-directed service delivery models.

## **Prevalence of Consumer-Directed Programs**

- One hundred thirty-nine (139) programs offering consumer-directed home and community-based (HCB) support services were identified nationwide.
- Every state, except Tennessee and the District of Columbia, offers at least one consumer-directed HCB support services program.
- Reasonably complete descriptive profiles were constructed for 129 programs.

## **Age and Permanence of Programs**

- Sixty-five percent (65%) of the consumer-directed HCB support services programs examined have been implemented since 1990 (17% within the past two years). Twenty-three percent (23%) of programs were implemented during the 1980s and 11% were implemented prior to 1980.
- Eighty-eight percent (88%) of the consumer-directed HCB support services programs are permanent whereas 12% are experimental (some operate under Medicaid "1115" research and demonstration authority, while others are state-funded pilot projects).

## **Number/Characteristics of Program Participants**

- An estimated 486,000 individuals receive services through consumer-directed HCB supportive services programs. Please note, this is a very rough estimate.

- A majority (58%) of consumer-directed HCB support services programs examined serve 1,000 or fewer participants.
- Twenty percent (20%) of programs serve 100 or fewer participants. Thirty-eight percent (38%) serve between 101 and 1,000 participants. Twenty-four percent (24%) serve between 1,001 and 5,000 participants and only 12% serve 5,001 or more participants. However, California's In-Home Supportive Services Program (which the inventory counts as two separate programs, one Medicaid-funded and one state-funded) accounts for slightly over half of all of the estimated participants in consumer-directed programs nationwide.
- The primary service groups for the consumer-directed HCB support services programs examined include adults aged 18-64 with physical disabilities (73%), elders (51%), adults with mental retardation (41%), adults with developmental disabilities (30%), persons with traumatic brain injury (38%), children with mental retardation/developmental disabilities (34%), children with physical disabilities (30%), persons with Alzheimer's Disease (29%), and persons receiving vocational rehabilitation (5%). Nineteen percent (19%) of programs serve other target groups such as adults or children with mental illness, children with traumatic brain injuries, persons with HIV/AIDS, persons with sight impairments (blind).

## **Restrictions on Participation**

- The majority of consumer-directed HCB support services programs (61%) examined have rules restricting who may participate in consumer-directed service programs.
- The most common restrictions are those limiting participation to individuals who have the ability to self-direct their services and supports (i.e., have physical disabilities but no cognitive impairments) or requiring individuals with cognitive impairment to have representatives (usually family members) willing to assist the individual in directing their support services (e.g., acting as the beneficiary's surrogate). Only 15% of programs strictly limit participation to self-directing individuals.
- A sizable minority of the consumer-directed HCB support services programs (31%) examined limit participation to adults aged 18-64.
- A few programs are designed to support informal caregiving and target family caregivers who are caring for persons in certain age groups or with certain kinds of conditions or disabilities exclusively.
- A few programs limit participation to individuals who are employed or who are actively seeking/training for employment.

## **Funding Sources**

- Medicaid is the major funding source for consumer-directed services. Eighty-four (84) programs (65%) rely in whole or in part on Medicaid funding. Sixty-five (65) programs (50%) receive funding through Medicaid HCB service waivers; 19 programs (15%) receive funding through Medicaid state plan covered services (i.e. the personal care service optional benefit).
- Fifty-five percent (55%) of the consumer-directed HCB support services programs examined are funded in whole or in part by state revenues (other than state share of Medicaid).
- Title XX (the Social Services Block Grant) is a funding source for only five (4%) of the consumer-directed support programs. Seventeen (17) programs (13%) receive funding from other sources (e.g., Title I, VII Part B, Title III Part E, IDEA, Part C, or county/municipal funds).

## **Covered Services**

- The most frequently covered services for the consumer-directed HCB support services programs examined are personal care (83%), homemaker/chore (60%), and respite (52%). Other covered services include transportation (47%), in home rehabilitation therapies (28%), companion (19%), and medical services (18%). Forty-eight percent (48%) of programs reported covering miscellaneous "other" services such as: handyman services, environmental modifications, special equipment, personal emergency response systems, vehicle modifications, home-delivered meals, adult day care, independent living skills, and, in some cases, "any support or service that allows a person to live successfully in the community."
- Most programs impose some -- albeit minimal -- restrictions with respect to the individuals consumers or their representatives may hire to provide support services (e.g., personal care, homemaker/chore or respite services). The most common restrictions (stemming from Medicaid law and regulations) disallow the hiring of spouses and parents or guardians of minor children. Representatives of consumers with cognitive impairments are typically (but not always) banned from hiring themselves.

## **Use of Intermediary Service Organizations**

- Seventy-four percent (74%) of consumer-directed HCB support services programs examined use "intermediary service organizations" (ISOs).

- The predominant role of ISOs is to enable program participants or their representatives to participate in consumer-directed support service programs. Some types of ISOs (Government and Vendor IRS Employer Agent-Fiscal ISOs) assist program participants and/or their representatives in performing employer-related tasks (e.g., computing, withholding, filing and depositing payroll taxes, processing payroll checks, arranging for employee benefits (e.g., workers compensation coverage). Some ISOs also verify legal immigration status and conduct criminal background checks on candidates for employment without being the legal employer of the worker and without the program participant receiving Medicaid benefits directly. Under these Fiscal ISO models the program participant or his/her representative is the legal employer of his/her support service worker.
- An IRS Employer Agent-Fiscal ISO may be a governmental or private (profit/non-profit) organization. The Internal Revenue Service distinguishes between governmental (IRS Rev. Proc. 80-4) and non-governmental (IRS Rev. Proc. 70-6) employer agents by prescribing specific procedures for each type to use in filing payroll taxes. Only 6% of the consumer-directed HCB support services programs examined used the government-based IRS Employer Agent or Third Party Payer approach. Forty-five percent (45%) of consumer-directed HCB support services programs examined used the Vendor IRS Employer Agent (e.g., Fiscal ISO) approach. A majority (70%) of Vendor "Employer Agent" ISOs are non-profit organizations.
- A minority of consumer-directed HCB support services programs (12%) examined use the ISO model referred to as the "Fiscal Conduit" ISO. This Fiscal ISO model coordinates the disbursing of program funds directly to adults/elders with disabilities or to family caregivers. The programs are primarily funded with state-only revenues. Many of the programs that use a Fiscal Conduit ISO are designed to offset care-related expenses incurred by family caregivers. The only Medicaid programs using the Fiscal Conduit ISO model are those with 1115 research and demonstration waivers to test this approach.
- Agency with Choice ISOs act as the legal employer of participant-hired workers while delegating authority to participants and/or their representatives for hiring/firing, training, and supervising the day-to-day activities of their support service workers. Twenty-one percent (21%) of consumer-directed HCB support services programs examined use the "Agency with Choice" ISO model. This ISO model is particularly effective in providing significant choice and control for individuals with cognitive impairments whose representative may not be willing or able to be the legal employer of the support service workers they recruit.
- A minority (13%) of consumer-directed HCB support services programs examined use the "Supportive" ISO model. Supportive ISOs tend to be special-purpose organizations or private individuals, often with case management



experience, whose primary role is to provide a variety of supportive services to program beneficiaries and/or their representatives (e.g., skills and advocacy training, counseling, maintaining worker registries and monitoring service quality and program participants' satisfaction with their support services).

- It should be noted that ISO models are not necessarily mutually exclusive. Some programs use more than one type of ISO (e.g., a Vendor Fiscal ISO and a Supportive ISO). In some cases the ISOs used by a consumer-directed support service program may meet the criteria for more than one ISO model (e.g., combined Fiscal and Supportive ISO or, in some cases, Support Brokerage). Also, information about ISO models used was not available for some programs.

## **Relationship to Managed Care Organizations**

- Currently, there is very little overlap between "consumer-direction" and "managed care" provided by managed care organizations.

## **Employment Status of Consumer-Directed Workers**

- Sixty-six percent (66%) of consumer-directed HCB support services programs examined treat all individuals hired directly by program participants as employees of the beneficiary or the beneficiary's representative.
- Twenty-one percent (21%) of consumer-directed HCB support services programs examined either offer or require the "Agency with Choice" ISO model under which consumer-hired workers become legal employees of the ISO with the program participant and/or his/her representative acting as the managing employer of his/her support service workers.
- A minority of programs allow some or all supportive service workers to be treated as "independent contractors" (i.e., self-employed professionals or sole proprietors of businesses). It should be noted that the employment status of support service workers can vary, appropriately, depending on skill level. For example, private duty nurses and therapists in private practice are typically viewed as self-employed professionals, whereas personal care aides and homemaker/chore workers are usually considered to be employees either of the service user or an agency, due to the level of direction and control being exercised over their job-related duties.
- A majority of entities serving as IRS Employer Agents use the IRS Forms 940/941 process to make quarterly tax filings; only a handful use the Schedule H. Although all IRS Employer Agents are not performing the IRS Form 940/941 in compliance with IRS rules, the IRS requires Employer Agents to file IRS Forms

## Medicaid's Relationships with ISOs and Consumer-Directed Workers

- Medicaid-funded programs vary in their designation of the legal "provider" of consumer-directed state plan personal care or 1915(c) waiver services. Medicaid law and regulations require "providers" of Medicaid benefits such as state plan personal care services or 1915(c) waiver services to execute provider agreements with the state Medicaid agency. The provider agreement establishes who is legally responsible for maintaining financial records with respect to Medicaid-funded services and for making those records available to the Medicaid agency upon demand.
- Fifty-one percent (51%) of consumer-directed HCB support service programs examined do not execute provider agreements with consumer-directed workers because, in most cases, the Medicaid provider agreement is executed with the ISO. This approach is typical where the ISO is either an Agency with Choice ISO (which is appropriate) or a Vendor IRS Employer Agent-Fiscal ISO which does not have a claims processing contract with the state but has been established more narrowly and specifically to facilitate the provision of consumer-directed services.
- A handful of programs are operating under 1115 research and demonstration authority which exempts the requirement to execute Medicaid provider agreements. However, in practice, the ISOs in these demonstrations do have provider agreements and billing numbers with the ISOs (not the support service worker his or herself) that receives Medicaid funds in the form of prospective payments.
- Under a number of programs operating with experimental 1115 demonstrations, the ISO may also act as a Fiscal Conduit disbursing Medicaid funds through to individual Medicaid beneficiaries who prefer to take full charge of their allowances. The ISO is still required to perform periodic audits of how beneficiaries use the funds to assure compliance with program restrictions on legitimate use of benefits.
- However, in the vast majority of, "cash and counseling" demonstrations, program participants use the Vendor IRS Employer Agent-Fiscal ISO option which provides them with budgeting, payroll and bill paying assistance with respect to the entire package of goods and services purchased with the participant's "cash" allowance. That is, funds earmarked for particular program participants remain in an account at the Vendor IRS Employer Agent-Fiscal ISO. Medicaid beneficiaries develop their own care plans, with some professional assistance, which may be provided by the same organization or a separate Supportive ISO. The Vendor

IRS Employer Agent-Fiscal ISO then processes payroll and pays invoices for goods and services out of funds in the ISO's accounts according to the program participant's service plan.

- Consumer-directed HCB support services programs examined executed a variety of different kinds of contracts with ISOs. Twenty-seven percent (27%) of programs executed administrative contracts only. Twenty-three percent (23%) executed only Medicaid service provider agreements. Twenty-six percent (26%) of programs executed both Medicaid provider agreements and administrative contracts. This includes programs with Medicaid and non-Medicaid or combined funding sources.
- Of the Medicaid-funded consumer-directed HCB support services programs examined for which information is available, 75% claim ISOs services as a program related expense (i.e., as providers of state plan personal care services and/or 1915(c) HCBS waiver services) and 25% claim ISOs services as a Medicaid program administration related expense.

## Quality Assurance

- Eighty-eight percent (88%) of the consumer-directed HCB support services programs examined have formal quality assurance requirements or processes.
- The most common method of monitoring quality involves the use of case managers (who may be state/county employees or ISO staff). At a minimum, service quality monitoring process uses the periodic participant reassessment process (required to verify participants' continued functional eligibility and assess possible changes in need for covered services) to also evaluate how participation in the consumer-directed program is affecting participants' health, safety, and satisfaction.
- The majority of consumer-directed HCB support services programs examined that use ISOs also set standards for monitoring the quality of services provided by the ISO. Consumer satisfaction measures and program/financial audits and other on-site record reviews are the most common techniques used.

**SOURCE:** EP&P Consulting, Inc. (Susan Flanagan, Project Director) for the HCBS Resource Network, a project jointly funded by the Office of the Assistant Secretary for Planning and Evaluation and the Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services.

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