CONSUMER-DIRECTED HOME AND COMMUNITY-BASED SERVICES

Background

Consumer-directed (CD) care – also called self-direction – empowers people with disabilities to make decisions about the services they want and how they wish to receive them. Often, they can hire family members, friends, or neighbors to provide care at home. This allows consumers to receive help with personal activities like bathing and dressing from people with whom they are comfortable. They can schedule aides during early mornings, nights, and weekends, when other paid help is hard to find, and they can pay for services like being driven to a store, something other programs may not allow.

While people who pay for home and community-based services (HCBS) with their own funds have always been able to direct their own services, it is only over the past decade that CD services have proliferated in public programs. Initially, this model was deemed most appropriate for adults with physical disabilities. However, it now includes children with developmental disabilities, people with cognitive disabilities, and older adults.

Definition of CD Services

Consumer-directed HCBS represents a philosophical approach to service delivery that maximizes consumers’ ability to assess their own needs, determine how and by whom they are met, and define what constitutes quality. Depending on the program, consumers may be able to

- choose which services to receive;
- select the days and times for service delivery;
- hire, manage, and terminate the workers of their choice, including family members; and
- manage their budgets by setting wages and/or purchasing items that enhance their independence (such as home modifications or assistive devices).

CD programs that serve people with cognitive disabilities or impairments generally require that a surrogate (usually a family member) help oversee services and make decisions.

Older People’s Preferences

A 1997 survey conducted for AARP found that more than three-fourths (76 percent) of people age 50 and older would prefer to manage their own home care services rather than receive services managed by an agency. A subsequent survey, in 2002, of people with disabilities age 50 and older found that only 15 percent preferred agency-directed services (see Figure 1 below). These results indicate that states should be encouraged to offer CD services as an option to older people with disabilities.

![Figure 1: Consumer Preferences for Managing and Paying Home Care Workers](image)

Source: AARP, Beyond 50:03

Not only does CD HCBS meet consumers’ preferences; it also can help address worker shortages, the need for culturally appropriate workers, and the availability of services in rural or other hard-to-reach areas, by expanding the pool of available workers. Consumers may receive more hours of service than under a traditional HCBS program because their individual budgets need not pay a home care agency’s overhead.

CD Programs and Their Characteristics

In 2004, a survey of CD programs serving older people was conducted by the National Association of State Units on Aging (NASUA). Data from the 40 states that responded identified 62 such programs, serving nearly 70,000 individuals. Thirty-eight percent of these programs had begun within the previous five years. The most common source of funding was Medicaid HCBS waivers (47 percent of programs); an additional 26 percent of programs received state dollars and 22 percent received Older Americans Act funds. See Figure 2 for types of services provided.
Figure 2: Percentage of Programs Providing Various Services

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Care</td>
<td>88%</td>
</tr>
<tr>
<td>Homemaker</td>
<td>88%</td>
</tr>
<tr>
<td>Home Modification</td>
<td>55%</td>
</tr>
<tr>
<td>Assistive Technology</td>
<td>52%</td>
</tr>
<tr>
<td>Respite</td>
<td>52%</td>
</tr>
<tr>
<td>Meal Service</td>
<td>48%</td>
</tr>
<tr>
<td>Medical Services</td>
<td>47%</td>
</tr>
<tr>
<td>Transportation</td>
<td>45%</td>
</tr>
<tr>
<td>Goods &amp; Services</td>
<td>38%</td>
</tr>
<tr>
<td>Caregiver Support</td>
<td>32%</td>
</tr>
<tr>
<td>Skilled Care</td>
<td>22%</td>
</tr>
<tr>
<td>Home Rehabilitation</td>
<td>9%</td>
</tr>
</tbody>
</table>

Source: NASUA 2004

Figure 3 illustrates the type of choices that participants are offered. The degree to which participants can control the delivery of services depends on the program.

Role of Fiscal Agents

Most people who participate in CD programs prefer to delegate the responsibility for payroll, tax withholding, etc. Most programs reimburse workers through fiscal agents (41 percent) or pay workers directly (22 percent) (NASUA).

Evaluation

Over three-quarters (78 percent) of state aging directors indicated that older consumers are highly satisfied with CD services (NASUA). One of the most rigorously evaluated CD programs is called Cash and Counseling (C&C). Started in three states (Arkansas, Florida, and New Jersey) in 1998, C&C has now expanded to 15 states. In the initial states, participants were randomly assigned to either a C&C or a traditional HCBS model. Compared with the control group, C&C participants
  - expressed greater satisfaction with services received;
  - reported a higher quality of life;
  - reported fewer unmet needs; and
  - indicated they had received more paid care. Initial concerns that CD programs would be subject to fraud and abuse have proven to be unfounded.

Expanding Consumer Direction

The federal government developed the Independence Plus waiver in 2002 to promote the use of CD in Medicaid. These waivers encourage person-centered planning, individualized budgeting, and self-directed services and supports. The Medicaid HCBS waiver application, revised in 2005, encourages states to include CD options.

As the use of CD programs grow, policymakers should consider issues such as the following:
  - Who will provide fiscal and support services, and how much should they be paid?
  - How should the amount of the cash allotment be determined: on an individual plan of care basis or over the program as a whole?
  - Should allowable service providers be expanded to include family members?
  - What oversight and monitoring would best ensure quality of care and fiscal integrity?

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