Cash & Counseling

Self-directed home and community long-term care

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Cash and Counseling: Self-directed home and community long-term care

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Abstract[2]

Cash and counseling is a service delivery model that offers recipients of publicly funded home- and community-based long-term care and their families the opportunity to self-direct the paid services and supports they receive in lieu of having them professionally prescribed and managed for them. Eligible program participants who elect to self-direct a budget for their home- and community-based services receive a monthly allowance that they may use to purchase a wide range of goods and services to meet their disability-related needs for functional assistance. Unspent funds may be carried over to save up for special purchases. The option to self-direct a budget allows service recipients and their family caregivers more choice and control, as their allowable spending may include non-traditional and customized services and supports that would not otherwise be available to them. Normally, professional case managers are restricted to developing service plans that include covered home- and community-based services, goods, and services that meet certain definitions and that are available only from program-authorized organizational providers. In particular, self-directing program participants may recruit individual home care aides rather than being required to obtain aide services from home care agencies, and their individual paid aides may be family members, friends, or neighbors. Self-directing program participants must, however, make use of the counseling services that the program pays for to assist them with managing their budgets. The "cash" component is not an unrestricted direct payment. Program participants' financial transactions are carried out via an accounting service that documents their spending, ensures that they do not go over budget, and ensures compliance with the tax, labor, and immigration laws applicable to employing individual home care aides. The counseling component of the cash and counseling model of self-directed home care also provides individualized advice and coaching to ensure that program participants do not use their funds for prohibited purposes; that the paperwork for the spending plan and, especially, employment is completed and submitted correctly; and that program participants with cognitive impairments have a designated representative (typically a family caregiver or friend who may not be a paid helper). The objective of this document is to explore how cash and counseling works, with examples of interventions in the United States, and how it is relevant for policy-making in Latin America and the Caribbean.

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Content

What is cash and counseling?

Cash and counseling programs are financial and care assistance programs—usually Medicaid programs—that provide beneficiaries with the choice and independence to decide how Medicaid funds budgeted for their long-term care are spent. They allow beneficiaries to decide what services are provided, how they are delivered, and who provides them. One particular feature of this program is that a friend or a relative may be hired as a caregiver. In this document, we will explore the main features of cash and counseling.

Who funds long-term care in the United States?

Medicaid is the primary public program that funds paid care for people who need help with activities of daily living that include personal care—such as bathing, dressing, transferring from bed to chair—and housekeeping tasks, like cooking and cleaning. Medicaid serves low-income people in need of long-term care of all ages and all types of disabling conditions, both physical and mental. About half of all home- and community-based care recipients are adults over age 65. Currently, **nearly 60% of Medicaid long-term care expenditures go toward home- and community-based services**. It took a long time to reorient this long-term care spending away from nursing homes because in the 1960s and 1970s, Medicaid almost exclusively funded institutional long-term care, stimulating a nursing home building boom. In this regard, Medicaid did not begin to invest significantly in home- and community-based services until the mid-1980s, and, even then, officials were cautious about paying for them for older people out of concern that it would supplement rather than substitute for nursing home use. As a result, spending on in home- and community-based services did not exceed 50% until 2013. As of 2019, the percentage of Medicaid long-term care expenditures going toward home- and community-based services had reached 57%.

What are the delivery modes of home and community-based services?

Home- and community-based services have two delivery modes: formally organized, professionally managed services, and self-directed services.

In the case of **formally organized, professional managed services**, most older people receiving Medicaid-funded home- and community-based services receive exclusively or primarily in-home personal care or homemaker/chore aide services. However, the state's menu of covered services might also include others such as adult day care and transportation to and from the centers (mostly for elders with dementia), home-delivered meals, transportation to and from medical appointments, respite care (so that unpaid family caregivers can regularly take a few hours or sometimes a few days off), and caregiver training. In addition, assistive technologies and home modifications (e.g. grab bars in the bathroom, wheelchair ramps) might also be covered but generally require the case manager to seek prior approval from superiors, a process that can take a year or more. State Medicaid programs set the hourly reimbursement rate for agency-delivered aide services. Typically, the agency's hourly reimbursement ratio is 60–40 for overhead versus aide labor. For example, if the agency's hourly rate is $20, a 40% overhead rate would mean $12 for aide labor (including wages, benefits, and employer payroll tax payments) and $8 for agency overhead (building rental, management and administrative staffing, recruitment, training, and supervision costs).

After the standardized in-home needs assessment determines the benefit to which an applicant is entitled (either a maximum number of aide hours or a monetary limit on the total cost of aide or other services), the Medicaid home- and community-based services recipient may be offered the opportunity to **self-direct their home- and community-based services**. In this case, it is possible to choose between ''employer authority'' or ''budget authority'' self-direction:

1. The most common form of self-directed services is called **"employer authority."** It affords service users and their families the choice to recruit independent providers (i.e., individual aides who are not agency employees). These individual aides may be family members, friends, neighbors, or, less frequently, individuals not previously known to the service recipient or his or her family. This mode of service delivery was pioneered in California in the early 1970s. Although it was initially championed by disability rights advocates (adults under age 65 who founded the independent living movement), it was also made available from the beginning to older people, with whom it proved very popular. More so than younger adults with disabilities, they wanted to be able to pay family caregivers. California continued to fund all or much of its In-Home Supportive Services program with state tax revenues only rather than Medicaid funding until 2003 because advocates did not want the program to have to adopt what they saw as Medicaid's unnecessarily "medicalized" model of service delivery. Federal regulations did not prohibit self-direction, but a regulation

explicitly permitting this service delivery mode for personal care was not published until 1997. By then consumer advocacy had caused states to consider offering options for self-directed services.

2. A broader approach to self-directed services, called **"budget authority" self-direction**, was introduced in the late 1990s. The Robert Wood Johnson Foundation, a private philanthropy, and the U.S. Department of Health and Human Services co-sponsored a social experiment in which 6,300 users of Medicaid home- and community-based services volunteered to participate in demonstration programs in three states: Arkansas, New Jersey, and Florida. The demonstration programs incorporated a controlled experimental design evaluation. Half of the volunteers were randomly assigned to the treatment group and given the opportunity to self-direct a budget which they could use to pay individual aides. Self-directing program participants could decide how many aide hours to purchase and negotiate hourly rates, so long as the hourly rate was at or higher than the federal or state required minimum wage. They could also use their funds to purchase other goods and services, which could be non-traditional, meaning they were not otherwise on the state's menu of covered services and need not be purchased from already enrolled Medicaid providers or suppliers at state-determined reimbursement rates. The only stipulation was that these goods and services had to meet disability-related needs. Funds could not be used to pay basic living expenses (e.g. food, rent) or luxury items (e.g. gifts for grandchildren), and could not be used to purchase alcohol or illegal drugs, or for gambling. Non-traditional purchases included microwave ovens so that meals prepared by aides could be frozen and reheated, a washer/dryer for a service user's apartment so that the aide could continue to do other tasks while doing laundry instead of having to use an outside laundromat, and a collapsible travel/back-up wheelchair. Often these items were used and therefore inexpensive, whereas the regular Medicaid program did not allow for the purchase of used equipment.

The "employer authority" self-direction mode remains dominant because it is older, having begun in California in 1974, and because California's In-Home Supportive Services program is by far the largest home- and community-based services program in the U.S., with a monthly caseload of 550,000, 95% of whom self-direct their aide services. This model spread to other states (e.g. MI, WI, WA, OR, MA, PA, and NY) in the 1990s. The more **expansive "budget authority" (cash and counseling) model began as an experiment in the late 1990s**. After positive findings from the random control trial evaluation, it became regularly available in Medicaid via regulation starting in 2003 and further expanded in legislation enacted in 2005 and 2009. A pre-pandemic national inventory estimated 1.2 million self-directing Medicaid home- and community-based services recipients (still nearly half in California). Early results from a new inventory indicate continuing growth, especially for "budget authority." For instance, the take-up rose from 27% in 2017 to 42% in New Jersey in 2021.

What was the Cash & Counseling experimental demonstration?

The demonstration program sponsored by the Robert Wood Johnson Foundation and U.S. Department of Health and Human Services across all three states was named Cash & Counseling. State officials rejected using the name Cash & Counseling for their programs because they thought the reference to cash was misleading. Experimental group participants did not literally receive cash payments in the form of a check or direct deposit to a bank account, and their use of the funds was regulated. There were several reasons why direct cash payments were ruled out. First, such payments could have been counted as income, causing treatment group participants to lose eligibility for other federal, state and local means-tested public benefits. While short-term waivers were available in some cases, these other non-Medicaid programs would have to be amended legislatively if the experiment were successful and Medicaid law made the model permanent. State officials also worried that the use of the term "cash" to describe the benefit could cause them serious political problems with state legislators. Some politicians were suspicious of low-income recipients of public benefits. They thought poor people who received cash payments would misuse them for inappropriate, possibly fraudulent purposes. They also believed that public programs should be accountable to taxpayers for how the monies were spent. Finally, preliminary surveys of potential demonstration participants found that most wanted the supportive counseling services. In fact, many said they would likely not volunteer to participate without having access to such assistance. Accordingly, each state gave its demonstration a state-specific name: "Independent Choices" in Arkansas, "Personal Preference" in New Jersey, and "Consumer-Directed Care" in Florida.

What is the difference between receiving direct ("cash") payments vs managing a consumer-directed budget?

Among the most innovative features of the cash and counseling mode of self-directed services is that **the monetary allocation is not an unrestricted cash payment** to users of home- and community-based services or their family caregivers. Unrestricted, tax-free cash benefits are very common in European long-term care programs. In some countries (e.g. Austria, Italy) this is almost the only mechanism for financing long-term care, at least at the national level. In other countries (e.g. Germany, Spain) home care recipients can choose whether to receive cash payments or services from formally organized providers who bill the program. Policymakers looking to learn from the expe-

rience of other countries are likely to find that the international comparative literature on publicly funded long-term care programs often portrays the choice in program design as a dichotomous one between cash-for-care direct payments and in-kind services from formally organized service providers. In such schema, the U.S. cash and counseling model of service delivery is classified as a form of cash for care—which is inaccurate. The European program most similar to "budget authority" self-direction in the U.S. is the personal budget available only to severely disabled home care users in the Netherlands (and chosen mostly by adults under age 65). This program, which requires use of an accounting service, was an early inspiration for the Cash & Counseling Demonstration. There are also some similarities with the French personalized autonomy allowance for dependent elderly over age 60. In France the allowance is direct deposited to the service user's personal bank account, but their use of the funds is highly regulated because they must follow a prescribed service plan (mostly directing them to purchase in-home aide services). The bank issues a special checkbook for paying individually hired aides to ensure compliance with all applicable legal requirements for employment (e.g. payroll tax payments). Family members other than spouses may be paid.

In the U.S., recipients of home- and community-based services who self-direct a budget do not have direct access to their funds. They develop their own spending plans for how they will use the funds. However, as part of **the counseling component of the model**, program participants' spending plans are reviewed before they can be implemented. This is to make sure that proposed spending is within the program's rules for permissible purchases (e.g. it clearly addresses disability-related needs), that planned spending meets legal requirements (e.g. it pays at least the state hourly minimum wage for workers and includes the employer's share of Social Security and other payroll taxes), and that total proposed spending does not exceed the individual's budget. Once the spending plan is approved and goes into effect**, all financial transactions made under the plan are performed for the self-directing program participant by an accounting service** (termed a financial management services entity) paid for with program funds. Most states contract with private-sector, for-profit or non-profit organizations. Self-directing program participants are free to revise their spending plans as they wish, but changes must be reviewed before taking effect. The accounting service along with one-on-one advice concerning each program participant's spending plan constitute the counseling component of the cash and counseling model. Typically, fees for counseling amount to no more than 10% of the total amount of each self-directing program participant's benefit (his/her budget plus counseling costs).

Why require paid family caregivers to have the legal status of employees?

In most European cash-for-care programs, many recipients of direct payments simply give those payments over to their family caregivers. Dependent elders often live with their adult children, and this extra tax-free income serves to improve the living standard of the whole household, which may also include a third generation. These funds may be used in ways that improve health and safety and make the performance of physically demanding functional assistance tasks easier and less time-consuming. For example, families may make home improvements that eliminate safety hazards or upgrade kitchens and bathrooms. The family may be able to afford more nutritious food. The drawback is that many countries want to boost female labor-force participation, and cash payments incentivize women to stay at home and perform traditional caregiving roles that are not recognized as work. When they are paid for at least a portion of the hours of care they provide, they are recognized as being in the labor force and gain a work history that may help them obtain future employment outside the home. Most of all, they do not have to choose between taking care of a relative (when they think they would provide better care than a paid stranger) and being employed and earning money that the household may need.

One of the most important roles of the accounting service is to act as the payroll agent for self-directing program participants who hire or fire and supervise individual aides. All paid aides have **the legal status of employees.** They are usually considered to be the domestic employees of the service users or service users' representatives (family caregivers who may not be paid helpers or paid for being representative decision-makers). California's In-Home Supportive Services program pioneered employment of family caregivers in the early 1970s, including spouses and parents of minor children. Initially, not all states that adopted options for self-directed services allowed hiring family members. For example, New York did not do so until 2012. All now permit paying family, but only 12 will pay spouses**. Family, like non-relatives, must be legally employed, in compliance with tax, labor, and immigration laws**. The policy's purpose is to allow family caregivers, if preferred, while also enabling caregivers to earn income they need and to otherwise benefit from participation in the paid labor force. Research indicates that paid aides who are family members provide better-quality care on average than non-relatives.

Prevalence of family as paid aides varies by state and, within states, by programs targeting different populations (ages, LTC conditions). In California's In-Home Supportive Services, 70% of paid aides are relatives, of whom more than half share a household with the service recipient. **Hiring relatives is especially popular among first- and second-generation Latino and Asian families**, and among the elderly who prefer to employ adult children (47–59% in Cash & Counseling Demonstration states). It is least popular among physically disabled adults under age 65. Parents are often employed to care for adult children with intellectual developmental disabilities. However, advocates have expressed some concerns that parents' long-term dependency on caregiving income may prevent children with intellectual and developmental disabilities (IDD) from maximizing their independence.

What about training to professionalize home care workers?

Research indicates that home- and community-based services **recipients define quality of aide care primarily in terms of relationship characteristics**—such as compatibility, trustworthiness, attentiveness, respect, reliability, and continuity—rather than technical competency in performing personal care tasks, which is typically the focus of formal training. **Agency aides do receive more formal training**. However, individually hired aides (family and nonrelatives) are more likely to accompany service recipients to doctor visits and be given information and instruction by doctors and nurses. State nurse practice acts allow them to be trained to perform routine skilled nursing tasks. **Self-direction allows for customized training**, which is likely to be more useful and less costly than one-size-fits-all standardized training. For example, nurses may train and delegate responsibility for performing routine skilled nursing tasks (e.g. bowel and bladder care) to aides, and this may trigger additional funding that allows these aides to be paid higher hourly wages. Counselors can help identify such needs, along with funding and sources for training. **Some state programs do impose mandatory training requirements, which tend to be minimal**. In no state does the standardized training exceed 80 hours for individually hired aides (which is also the current maximum in any state for agency-employed aides), and required hours for paid family caregivers (e.g. adult children of dependent elders) may be lower.

Who is eligible for self-directed services?

Prior to choosing between traditional, formally organized services and the option to self-direct, **all applicants for home- and community-based services receive an in-home needs assessment to determine eligibility and coverage**. The assessor (who may be called a "case manager") administers a standardized needs assessment instrument, and the person's score determines the benefit (e.g., authorized hours of aide service or monetary limit on spending for a range of home- and community-based services). Even when state benefits are generous, paid care rarely covers more than 20%–25% of hours of help with daily living tasks that beneficiaries receive. Those who choose traditional formal supports are assigned or may be allowed to choose a case manager (who may be the assessor, but more often is someone different). Self-directing beneficiaries exercising "budget authority" get support from "counselors." However, another alternative is for the financial management services entity to be deemed the legal co-employer, but only for tax and labor law compliance purposes. In some programs, financial management and individualized counseling services are provided by the same private sector (non-profit or for-profit) organizations. In other programs,

these support services are provided separately. For example, some states may contract with only one financial management services entity to carry out financial transactions in accordance with program participants' spending plans but provide a list of self-employed individuals whom the state has accredited to provide one-on-one counseling and allow program participants to choose their counselors from that list.

Program participants or their representatives perform other employer functions such as hiring or firing, scheduling, and assigning and supervising tasks on a daily basis. Self-directing program participants may also be wholly or partially responsible for training their aides and determining hourly wages, within permissible limits

With few exceptions, **anyone eligible for home- and community-based services can choose to self-direct his or her services under either the employer or budget authority options**. However, those eligible for home- and community-based services who are cognitively impaired must have designated representatives to assist them or act as their surrogate decision-makers. Others may choose to name a representative even if they are not required to do so. Representatives are typically close family or friends. They may not be paid for serving as representatives and may not be hired as paid aides. Virtually all program participants with IDD have representatives; a majority of older Americans have representatives; and a minority of physically disabled adults under age 65 have representatives.

Self-direction has several advantages but is not necessarily right for everyone. Self-directing beneficiaries may find the added responsibilities of decision-making onerous and may not be able to identify suitable representatives to assist them. Recruiting and managing individual aides may be especially challenging if beneficiaries do not have family, friends, or neighbors available to hire or that they wish to employ. Worker registries are among the support services that programs can provide to help self-directing program participants identify non-relatives who are interested in working directly for those in need of aide services and their families instead of becoming home care agency employees. Until recently, these registries were telephonic, but they are increasingly available online.

What are the differences between case management and counseling?

The role of counselors differs from that of case managers who develop care plans for users of formally organized services, as it is advisory and not prescriptive. Counselors do review spending plans and check the math to make sure that the proposed spending will not exceed the available budget. If self-directing program participants include in their proposed spending plans goods and

services that may not clearly meet a disability-related need, the counselor takes the question to state officials for a decision. For example, early on in New Jersey, a program participant with multiple sclerosis who lived alone with small children requested state permission via her counselor to purchase a new sofa with a hard cushion because she often fell when getting up from her existing soft-cushion sofa and then had to call a neighbor or 911 to help her off the floor when no adult helper was present. Although the state program director determined that this was indeed a legitimate disability-related need and therefore a permissible purchase, the program participant ended up persuading a relative to gift her a used, hard-cushion sofa from the relative's home that the relative had decided to replace. In Arkansas, state officials approved the purchase of a stackable washer/dryer for a program participant's apartment. Although this would be considered a convenience for a non-disabled individual, they determined that it met a legitimate, disability-related need for the program participant, who was a blind amputee. He could not safely take his laundry to an external laundromat and, if his paid aide had had to do so, she could not have accomplished other necessary tasks for her consumer/employer.

Counselors are required to check in periodically with program participants and are expected to be on the lookout for any signs of abuse, mistreatment, or exploitation of service users by either paid helpers or unpaid family caregivers. The financial management service may also alert a program participant's counselor if, for example, timesheets for aides are no longer being submitted, which may be an indication of self-neglect or that the program participant may be experiencing difficulties with self-directing aide services. If they observe these signs, counselors are required to report them or intervene. Research indicates that when counselors identified such concerns, they could usually resolve them by requiring the designation or replacement of a representative.

In addition, counselors often assist self-directing program participants with employment-related paperwork, which given tax, labor, and immigration laws in the U.S., may initially be quite daunting for program participants For example, they may help them write their requirements and expectations for paid aides in an employment contract that both the consumer or employer and the aide agree upon and sign. Counselors may also coach program participants in how to interview and check the references and credentials of prospective workers, but they cannot otherwise participate in hiring and firing or supervising aides. They may also help self-directing program participants brainstorm creative if somewhat unorthodox solutions to their disability-related needs that rely on community resources (including some volunteer or other no-cost assistance) rather than formal home- and community-based services providers.

Case management has historically followed a medical model. Case managers (usually nurses or social workers) assess functional assistance needs and develop a service plan—implicitly analogous to a physician diagnosing a patient and prescribing a treatment plan. However, identifying functional assistance needs does not require the medical knowledge necessary to diagnose illness. Also, Medicaid does not allow case managers for home- and community-based services the discretionary authority given to physicians. They can authorize only the services defined and listed on each

state program's menu of covered services, subject to coverage limits. Meanwhile, **counseling is a social model** that recognizes that the purpose of home- and community-based services is to help people with functional limitations live as normally as possible, according to their perceived needs, preferences, and priorities.

Finally, what are the advantages of self-direction?

1. **More choice and control for service users and families:** Service users and their families are able to exercise greater choice and control, especially when they not only recruit individual paid aides but also manage a budget. **The services and supports they include in their spending plans reflect their perceived needs and priorities**. Home care is labor-intensive and expensive. As a result, even when countries provide social insurance coverage, unpaid family caregivers continue to provide a majority of the functional assistance required. In Germany, for example, when agencies send paid aides, it is estimated that unpaid family caregivers still provide 70% of the hours of help needed.

2. **Better outcomes:** A substantial evaluation research literature resulted from the Cash & Counseling Demonstration that included a random control trial evaluation, as well as from other studies of self-direction in California and elsewhere that compare the outcomes of these programs with those of formally organized, professionally managed services. On all dimensions measured (service users' satisfaction with services and quality of life, reports of unmet need for functional assistance, adverse outcomes of poor care such as bedsores, reported stress and burden on family caregivers, cost of care, etc.) **outcomes for self-directing program participants were usually better and never worse than for formally organized, professionally managed services**. Moreover, reported job satisfaction (with pay and working conditions) was greater for aides hired directly by self-directing service users than for agency-employed aides.

3. **Honoring preferences for family caregiving:** What is the rationale for requiring family caregivers who want to provide home care to their relatives but need the income from employment to take jobs outside the home while others—usually strangers—are paid to do the job they would have preferred? This arrangement makes little sense, especially if the hourly wage for alternative employment available to them outside the home is the same or lower. **Many program participants and their families prefer to directly hire individual paid aides and most often choose individuals whom they already know and trust**, like family, friends, or neighbors. U.S. research indicates that most unpaid family caregivers who become paid aides continue to provide additional hours of unpaid care. For non-relatives employed as paid aides to be asked or even volunteer to work additional unpaid hours violates the Fair Labor Standards Act.

4. **Cost effectiveness: Administrative costs are lower when self-directing program participants recruit and supervise individual aides**. Home care agency overhead typically accounts for 40–60% of hourly rates, whereas the accounting service and counseling cost 10–20%. The savings can be used by the government to serve more individuals and allow for more generous benefits (including better pay and benefits for home care workers) for the same total amount that formally organized, professionally managed home- and community-based services would have cost.

5. **Continuity of care: Self-direction is associated with greater continuity of care**, as there is considerably less turnover among aides. Annual turnover among agency workers in the U.S. averages 60%. Agency aides are often absent or quit unexpectedly, and agencies routinely reassign aides to other clients for convenience of scheduling and to minimize travel time between clients.

6. **Immediately having enough providers to meet demand:** When public funding for home- and community-based services first becomes available, there are typically few formal services providers. **It can easily take several years for a robust network of formal services providers to emerge**. As a result, if eligible individuals must get aide services from home care agencies, there are likely to be long waiting lists. Meanwhile, unpaid, experienced family caregivers already exist and likely could use the income from paid employment. It is also easier to establish the accounting services that self-directed services programs require. Most states contract with only one or a limited number. The challenge of recruiting and training local counselors is about the same—and no greater—than that of recruiting adequate numbers of case managers.

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