

CONSUMER-DIRECTED LONG-TERM CARE: PARTICIPANTS' EXPERIENCES IN FIVE COUNTRIES

Introduction

In response to significant growth in the population needing long-term care, predicted declines in the availability of caregivers, and increasing pressure from working-age adults with disabilities, many countries, including the United States, have been exploring innovative ways to improve their publicly funded long-term care systems. One of these innovations is consumer-directed long-term care.

The National Institute on Consumer-Directed Long-Term Care defines consumer-direction as “a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive. Consumer-direction ranges from the individual independently making all decisions and managing services directly, to an individual using a representative to manage needed services. Choice and control are both key elements of any consumer-directed system” (National Council on the Aging 1996).

Some consumer-directed long-term care programs permit consumers with disabilities to perform tasks such as choosing, scheduling, or training caregivers, while others provide cash allowances that enable people to purchase and manage their own supportive services. Although many consumer-directed programs have targeted persons under age 65, some countries have extended self-

management programs to older persons as well. This issue brief examines the experiences of people who have participated in these publicly funded programs.

The report is organized into three main sections. It begins with a brief description of the evolution of consumer-directed programs in the United States (U.S.) and the availability of such programs in this country and abroad.

The next section of the report reviews six studies of consumer-directed programs in five countries — Austria, Germany, France, the Netherlands, and the United States. The focus of this review is the actual experience of participants in these consumer-directed, long-term care programs. Accordingly, the studies are divided into three categories: 1) surveys of beneficiaries of social insurance programs; 2) evaluations of demonstration projects that provided cash to persons with disabilities; and 3) surveys of beneficiaries of means-tested programs. Detailed tables provide information about each study's purpose, sample population, research methods, results, and limitations.

The conclusion examines the findings of the studies, including how participants perceive choice, control, and quality of care, as well as the quantity of services purchased under consumer-directed care. The issue brief also explores the policy implications of these

study results for the U.S. publicly funded long-term care system.

Origins of Consumer-Directed Long-Term Care in the United States

The origins of consumer-directed care in the United States can be traced to the Independent Living Movement of the 1970s. In an effort to become part of mainstream society, working-age adults with disabilities began demanding the right to manage and receive their services in home and community settings. The movement had to battle societal stereotypes, which held that persons with disabilities were vulnerable and in need of protection (Cohen 1988; Simon-Rusinowitz and Hofland 1993; Dejong and Wenker 1983).

Yet the philosophy of the Independent Living Movement has been somewhat slow to take hold among older persons with disabilities and their advocates. Simon-Rusinowitz and Hofland (1993) describe the views that the aging and disability advocacy communities have had regarding consumer-direction in the United States. According to these researchers, the aging community's primary goals for long-term care include maintaining persons in their own homes and avoiding nursing homes for as long as possible. The researchers observed that the goals of the disability community emphasize consumer independence, control, choice, and services necessary to participate fully in society.

The publicly funded long-term care system in the United States generally uses case managers to arrange and monitor supportive services in the home

and community. A number of programs, however, provide significant opportunities for beneficiaries to direct their own long-term care, rather than relying on case managers to do so. In addition, national foundations and policymakers are paying increasing attention to the issues of independence and choice in long-term care. These trends reflect the continuing influence of the decades-old Independent Living Movement.

Independent living movements among working-age adults with disabilities have also emerged in other countries. In some Western European nations, these movements have succeeded in bringing about major change.

Availability of Consumer-Directed Programs in the United States and Other Countries

Although there is no comprehensive catalogue of consumer-directed long-term care programs in the United States and around the world, several studies document a number of these programs. Flanagan and Green (1997) described 23 programs in 11 states, while Scala and Mayberry (1997) reported on 14 programs in as many states. Cameron and Firman (1995) reported that most Western industrialized countries provide some sort of long-term care allowance for persons with disabilities. These studies sometimes provide detailed descriptions of consumer-directed programs, but they generally do not address the experiences of participants in this type of program.

Methodology

A comprehensive search of published and unpublished literature was conducted to identify the studies reviewed for this issue brief. Several bibliographical databases were searched, as were as the archives of the National Institute on Consumer-Directed Long-Term Care, which is housed at the National Council on Aging. In addition, experts and disability advocates were contacted to identify other relevant studies.

Research included in this review met two key criteria: (1) the studies were conducted under government auspices or by academic or survey researchers; and (2) older persons were a major subset of the study population. Using these criteria, evaluations of demonstration projects or surveys were identified in Austria, France, Germany, the Netherlands, and the United States.

Participants' Experiences in Consumer-Directed Programs

This section briefly describes the consumer-directed programs studied and then analyzes the experiences of participants in each of them. For ease of analysis, the studies are divided into three categories according to the nature of the programs and the research involved:

1. Surveys of beneficiaries of social insurance programs. Programs in Austria and Germany fall into this category.

2. Evaluations of demonstration projects that provided cash to persons with disabilities. Projects in France and the Netherlands are included here.
3. Surveys of beneficiaries of *means-tested* programs (i.e., programs that require persons with disabilities to be poor or to impoverish themselves to receive benefits). Studies from the United States are in this category.

Each category includes a discussion of the context in which consumer-directed programs were implemented or tested, along with a summary of the experiences of program beneficiaries and participants. For each category, an associated table provides detailed information about (1) the purposes of the research, (2) the study populations, (3) the research and analytic methods, (4) the findings of the study, and (5) the limitations of the research.

1. Social Insurance Programs

Context

In the early 1990s, in response to pressure from working-age adults with disabilities, Austria and Germany implemented large social insurance programs that provided cash allowances to persons with disabilities. Austria's Federal Long-Term Care Allowance Act, implemented in 1994, was designed to (1) provide a uniform payment to help compensate for care-related expenses, (2) promote a "self-determined" lifestyle, (3) enable people with disabilities to remain in their own homes, (4) encourage families to provide

more care, and (5) link previously existing provincial allowances (Badelt et al. 1997). General tax revenues and payments from employers and employees fund this program (Rubisch et al. 1995).

To be eligible for the Austrian program, Rubisch et al. (1995) report that applicants must be at least three years old, have a permanent need for personal assistance, and require 50 or more hours of care per month. No means test is imposed on applicants. There are seven benefit levels, which in 1994 ranged from \$250 to \$2,000 per month. The amount of the benefit increases as dependency rises. Reports on how money is used must be filed, and local authorities can terminate the allowance if it is “flagrantly misused” (Keigher 1997). Beneficiaries with cognitive impairment may have someone appointed to manage their allowance. In 1995, beneficiaries who lived in the community were surveyed about their experience with the new allowance (Badelt et al. 1997).

Germany’s Social Dependency Insurance program is similar to Austria’s allowance program. In 1995, insurance benefits were made available to persons with disabilities, regardless of age. The program’s purposes include the following: 1) compensation of beneficiaries for the cost of care; 2) promotion of home care; and 3) improvement in the lives of beneficiaries and their caregivers (Reichert 1997).

Germany’s program recognizes three levels of dependency. The lowest level applies to individuals who have limitations in two or more activities of

daily living (ADLs) and need help at least once a day; the highest level is reserved for those who need assistance “day and night” (Schneider 1997). Service benefits are available for those in nursing homes if home care or day care is not possible. Beneficiaries in the home and community can select one of three options available to them: a cash benefit; agency services which have twice the monetary value of the cash; or a combination of the two (referred to hereafter as a combination benefit). In 1996, persons with the lowest level of dependency received 400 DM (\$250 in U.S. currency) a month, whereas the service benefit was 750 DM (\$468) a month.

In the program’s first year of operation, 84 percent of beneficiaries with the lowest level of dependency chose the cash benefit, as did 67 percent of those with the highest level. The cash must be used to help meet the beneficiary’s long-term care needs. Beneficiaries who choose cash must receive periodic counseling, as well as visits from professionals who help assure quality and proper expenditure of the cash (Schneider 1997). A payroll tax on employees and employers provides funding for the program; retirees and their pension funds also pay a premium. German beneficiaries were surveyed about the new program in 1996 (Runde et al. 1996).

Study Methods and Results

The studies of the experience of program participants in Austria (Badelt et al. 1997) and Germany (Runde et al. 1996) were based on surveys mailed to a random sample of program beneficiaries

living in the community. The Austrians also surveyed the beneficiaries' primary caregivers. The response rate for the Austrian survey was about 50 percent, yielding 3,120 respondents. In Germany, the response rate was about 30 percent and yielded 10,400 respondents. In both countries, about 75 percent of respondents were age 65 and over, and many had severe disabilities. Respondents were representative of beneficiaries living in the community.

The results indicate that cash payments are used primarily as intended -- to help compensate caregivers, to purchase additional home care services, and to make home modifications to meet the needs of beneficiaries. In Austria, for example, 81 percent of beneficiary respondents reported that the allowance helped them compensate their relatives for care, and 29 percent of caregiver respondents used the cash for home modifications.

Cash assistance gave the majority of beneficiaries more independence, choice, and control in their lives. In Austria, 65 percent of beneficiary respondents reported that they had greater freedom to select their caregivers, and 71 percent reported that they were better able to handle daily pressures than before they received the allowance.

In Germany, 72 percent of respondents felt that the insurance program was necessary to preserve their independence. German beneficiaries of cash assistance clearly valued the range of choices available to them. Eighty-five percent of cash-assistance respondents and 61 percent of combination-benefit respondents saw an advantage in being

free to decide how to use their benefits. This feature was of lesser value to respondents receiving agency services, only 27 percent of whom perceived such an advantage.

Information on quality of care was available only from the German study. Forty-three percent of all respondents indicated that quality of care had improved as a result of the new benefits, 55 percent indicated that quality remained the same, and only two percent felt that quality had deteriorated.

In both Germany and Austria, therefore, programs that provide cash to people with disabilities enhanced their perceptions of independence and choice. A significant share of German respondents, moreover, reported that the quality of their care improved as a result of the new insurance benefit.

Caregivers helped many respondents to complete the surveys, and the effect of this assistance on responses is unclear. Nevertheless, the results of both surveys and the strong preference of German respondents for cash payments suggest that this type of benefit is likely to be popular among people with disabilities. Table 1 presents the detailed results of the surveys conducted in Austria and Germany.

2. Demonstration Programs

Context

Unlike the studies in Austria and Germany that assessed beneficiaries' experiences with new governmental programs, the demonstration projects in France and the Netherlands were

established to test new options for providing long-term care. The French established a demonstration project to test implementation of the *prestation dependance*, a non-means-tested allowance for older persons with disabilities (Davies 1995). The effects of the allowance were measured in a survey of participants (Gilles et al. 1995; Simon and Martin 1996). The Netherlands sponsored its demonstration program to determine whether cash assistance (known as “client budgets”) would lead to greater consumer choice and higher quality of care for participants, as well as increased competition among providers (Miltenburg et al. 1996).

Study Methods and Results

Different research methodologies were used in the French and Netherlands experiments. France conducted a demonstration project in 12 of its departments (i.e. provinces) to test implementation of an allowance for people with disabilities who were age 60 and over. Two of the departments provided in-kind services only, four offered cash payments, and six provided a mixture of both. About 75 percent of participants received all or a portion of their benefit through a cash allowance. All departments using the cash payment option had a system for verifying how the money was spent.

The French demonstration participants were contacted by mail to ascertain their willingness to be interviewed at home. About 28 percent refused to participate, had died, or were no longer living in the community. About 700 randomly selected

participants were interviewed at home using a standard protocol, 87 percent of them accompanied by a family member or an aide. The average age of respondents was 81, and 19 percent were severely disabled (Gilles et al. 1995; Simon and Martin 1996).

In the Netherlands, 2,615 current or future users of home care in two cities were asked to participate in an evaluation of cash assistance. Children and people with dementia could participate only if they had a surrogate decision maker. Fifty-five percent of those contacted -- 1,440 people -- refused to participate because they were satisfied with current services or did not want to be part of the demonstration.

The project enrolled more than 1,000 people of all ages, randomly assigning them to one of three groups: 1) an experimental group that was offered a choice between cash or agency services; 2) a second experimental group that was offered the same choice with the addition of optional counseling for participants that chose cash; and 3) a control group that received only standard agency services. The benefit was set at 100 percent of the cost of services, or \$635 a month on average.

About 45 percent of all participants in the two experimental groups chose cash; among those age 75 and over in the experimental groups, however, only 30 percent chose cash. The average age of those choosing cash was 70, while the average age of those choosing agency services was 74. Persons new to home care were significantly more likely to choose cash. Almost all participants in the experimental groups used the cash to

purchase services, and two-thirds purchased nursing and home care services exclusively (Miltenburg et al. 1996).

Participants in the Netherlands' experimental groups were able to purchase more services than those in the control group because competition among providers produced lower prices in the private market.

Eighty-five percent of those in the experimental groups who chose cash said that they had the ability to choose and control their services; only 46 percent of control group participants indicated that they had this ability. About 90 percent of those in the experimental groups who chose cash would either do so again or recommend cash assistance to others.

Participants receiving cash assistance reported greater satisfaction with quality of care, measured in terms of both worker efficiency and continuity of care, than did those in the control group. Based on the demonstration project's findings regarding quality of life and care, the Netherlands implemented a permanent cash assistance program for people with disabilities.

Independence and choice were important to only a minority of the French respondents. One-third of the French respondents believed that an advantage of the cash benefit was that it provided more control over care providers. At the same time, two-thirds of French respondents believed that an advantage of agency services was freedom from administrative tasks such as advancing cash to workers, visiting

governmental offices to verify workers' salaries, and recruiting workers.

More than 90 percent of French respondents were satisfied with their workers, regardless of how the allowance was administered, and 64 percent said the allowance had improved their lives.

Fifty-four percent of French respondents said that the allowance enabled them to hire home care workers, about a third of whom were friends or family members. Twenty-two percent of respondents indicated that the allowance helped them avoid a retirement home.

Both studies support the premise that a consumer-directed option can provide beneficiaries with independence, choice, and control. The results of these studies are also consistent with the German study's finding that 43 percent of German respondents perceived that the quality of their care had improved as a result of the new benefit. Study results in the Netherlands are particularly strong, given the randomized assignment of participants to treatment and control groups. The likelihood of choosing cash assistance decreased with age in the Netherlands. Finally, the French study indicates that administrative tasks associated with the employment of workers may present barriers to those who want to manage their own services.

Over half of those asked to participate in the Netherlands' demonstration project refused to do so. In France, where more than 70 percent of those contacted agreed to be interviewed, those who would not or could not participate tended to be among the most

frail. Thus, the results of the two studies may not be representative of the entire population with disabilities, particularly those who are most frail. Table 2 provides detailed results of the French and Dutch demonstration projects.

In the French study, as in the Austrian and German studies, many respondents received assistance from caregivers in answering questions.

3. Means-Tested Programs in the United States

Context

In the Austrian, German, French, and Dutch studies, participants with disabilities received benefits regardless of their income level. This section of the paper examines two surveys of Medicaid beneficiaries in the United States. Medicaid, a means-tested program, is the major source of public funding for long-term care in the United States. A number of states offer opportunities for consumer-direction to Medicaid beneficiaries.

Two studies of Medicaid programs with consumer-direction features have been conducted: one focused on Medicaid recipients in California, while the other surveyed beneficiaries in Maryland, Michigan, and Texas. The most recent is the 1998 study of California's In-Home Supportive Services (IHSS) program (Benjamin et al. 1998). The IHSS program provides beneficiaries with access to consumer-directed and agency-directed long-term care models. The program spends about \$1 billion a year on 200,000 beneficiaries of all ages. To be eligible

for the program, people must (1) be aged, blind, or disabled; (2) live at home; and (3) meet Medi-Cal's (i.e., Medicaid's) financial and functional eligibility criteria. California's Residual Program, funded entirely by the state, is available for people who meet all but the income criteria. About 14 percent of beneficiaries have income too high for Medicaid eligibility and are served by the IHSS Residual Program.

County workers assess the home care needs of applicants based on impairments in functioning and then determine the hours of services needed to maintain people in their own homes. No beneficiary can receive authorization for more than 283 hours of care per month. The cost caps for individual beneficiaries are determined by multiplying the hours of services authorized by the minimum wage (Benjamin et al. 1998).

Throughout the state, the IHSS program offers a consumer-directed model of care in which beneficiaries are responsible for recruiting, hiring, training, and supervising their workers. The state pays these workers directly after the beneficiary certifies the number of hours worked. Beneficiaries can hire any family member they choose, including spouses; more than 40 percent of consumer-directed beneficiaries have hired family members.

In 12 of California's 58 counties, IHSS also offers an agency-directed model in which home care agencies coordinate all services for clients, and hire, train, and pay workers. Case managers in these counties assign people to either the agency-directed or

consumer-directed model. People who live alone, who are considered unable or unwilling to manage their care, and who have relatively few care needs are generally assigned to the agency-directed model. Those with heavy care needs are usually assigned to consumer-directed care. Because the workers who work in consumer-directed care are paid only minimum wage, persons with heavy care needs are able to purchase more services than if they had to rely on agency services, which cost about \$14 an hour (Benjamin et al. 1998).

Study Method and Results

Benjamin et al. (1998) conducted a telephone survey of a stratified random sample of about 1,100 respondents in the consumer-directed and agency-directed models. The respondents were age 18 or over and did not have severe cognitive impairments. The survey response rate was 78 percent. The purposes of the survey were (1) to compare outcomes for respondents in the two care models; and (2) within the consumer-directed model, to compare outcomes for respondents who hired family workers with outcomes for those with non-family workers.

About half of consumer-directed and agency-directed respondents were age 65 and over. However, consumer-directed respondents were significantly less likely than agency-directed respondents to be female, white, and living alone. Consumer-directed respondents also had lower educational levels than agency-directed respondents. In addition, 52 percent of consumer-directed respondents had severe disabilities (i.e., needing 20 or more hours of services a

week) compared with only 13 percent of agency-directed respondents.

Independent of service model, age was a significant predictor of certain outcomes. In general, persons over age 65 had fewer unmet instrumental activities of daily living (IADL) needs but were significantly less satisfied with their services and choice of services than those under age 65. Persons over age 65 also reported less satisfaction with the worker's ability to assist them with tasks inside and outside of the home than persons under age 65.

When the researchers controlled for many of the differences between the two groups, including age, beneficiaries' outcomes varied by model type. Thus, the effects reported below are attributed solely to differences in the models.

Model type was significantly related to six beneficiary outcomes. Consumer-directed respondents reported more satisfaction with their services and freedom to select them, a stronger preference for the role of managing services, higher perceived quality of care, and higher emotional, social, and physical well-being than did agency-directed respondents. Consumer-directed respondents also reported greater satisfaction with the providers' ability to assist them in doing things inside and outside of the home than did agency-directed clients. Other differences in outcomes between the two groups were not significant.

Within the consumer-directed model, provider type was a significant predictor of four client outcomes. Respondents with family providers

reported a higher sense of security, more satisfaction with their services and selection of them, a stronger preference for the role of managing services, and greater satisfaction with the providers' interpersonal manner than clients with non-family providers. Other differences in outcomes between the two types of providers were not significant.

In the second study of Medicaid programs with consumer-direction features, Taylor et al. (1991) conducted in-person interviews with 879 Medicaid beneficiaries who were receiving home care in Maryland, Michigan, and Texas. Survey response rates were above 90 percent in each of the three states. About 80 percent of respondents were age 70 or over, and half the sample had difficulty performing two or more activities of daily living. None of the respondents had cognitive impairments. In an effort to determine how consumer choice affects beneficiaries' satisfaction with their lives and their workers, the researchers constructed an index of choice to compare the responses of those who reported little or no choice regarding their home care providers with those who had a great deal of choice.

The consistent result was that those with choice reported more satisfaction with their services than those without choice. For example, about 60 percent of those scoring zero (little choice) on the choice scale were very satisfied with their aides compared with 90 percent of those with scores of four or five (a great deal of choice). About half of those scoring zero, but 90 percent of those scoring four or five, said that their aides came to work as expected. Further, about half of those scoring zero said

their aides knew how to get things done very well compared with almost all of those scoring four or five (Taylor et al. 1991; Doty et al. 1996).

To summarize, both studies demonstrate the positive effects of beneficiary choice, control, and perceptions of quality of care when Medicaid beneficiaries have opportunities to direct their own long-term care. For those who hire family members to care for them, Benjamin et al. (1998) found additional benefits in terms of an enhanced sense of security and greater satisfaction with services. A limitation of both studies, however, is the exclusion of persons with cognitive impairments. Table 3 provides a detailed summary of the U.S. studies.

Conclusion

Most of the findings emerging from the studies reviewed support the premise that persons with disabilities would experience better quality of life if they had more opportunities to manage their own long-term care. At the same time, the study results underscore the importance of ensuring that programs remain flexible by providing beneficiaries with a range of service management options.

Findings

The most consistent finding in these studies is that persons managing their own long-term care services experienced more choice and control in their lives than those using agency services. This finding was true of German beneficiaries, the Dutch participants who chose cash in the Netherlands' demonstration

project, and the Medicaid beneficiaries in the United States who had significant control over their long-term care services. The Austrian study indicates beneficiaries believed that the cash assistance program gave them greater freedom to select their workers. However, Austrians may have felt this way simply because they were receiving a new benefit. The results from France are more equivocal, in part because participants in that demonstration program expressed frustration with certain administrative tasks.

Another finding is that participants' perceptions of quality of care do not appear to suffer under consumer-directed programs. On the contrary, results from the Netherlands indicate that persons who chose cash assistance perceived that their quality of care had improved. The results of the two Medicaid studies are consistent with these findings. In addition, the California study shows that consumer-directed respondents felt higher emotional, social, and physical well-being than their agency-directed counterparts.

A third finding is that individuals in the Netherlands and California who were in consumer-directed programs received more hours of service than those who used agency workers. This is because workers in consumer-directed programs cost less to hire than agency personnel.

Factors to Consider

While contemplating these positive results, several important factors should be kept in mind. The primary factor is that not everyone wishes to manage his or her own services. The results from

the Netherlands suggest that, as disability and age increase, the percentage of persons who wish to manage their own care decreases. In addition, the French study shows that the administrative tasks associated with employing workers may present obstacles for some. The fact that more than half of those approached to participate in the Netherlands' demonstration project declined to do so indicates that a large percentage of potential beneficiaries of a cash assistance program may not want the accompanying responsibilities or may be content with the current long-term care system.

Another factor to bear in mind is that a number of beneficiaries received help in responding to the surveys. How this assistance may have influenced the respondents' answers is unclear.

A major unanswered question is how persons with cognitive impairment would fare under systems with significant consumer-direction. Most of the studies either did not include persons with cognitive impairment or relied on proxy respondents. For this population, many of the tasks associated with self-management would require the participation of a responsible party. Further research is needed in this area.

Policy Implications

The significant positive results of providing beneficiaries the opportunity to manage their own long-term care services suggest that policymakers should consider how they might make more of these opportunities available. One option is to allow beneficiaries to

hire family and friends to provide care. The programs in Austria and Germany were designed to support such an informal care network, and the evidence shows that some of the cash assistance was used to pay family and friends to provide care. In addition, California beneficiaries who hired family felt safer and had better interpersonal relationships with their caregivers than those who hired non-family providers.

Another option is to provide beneficiaries with the opportunity to hire, supervise, train, or fire their workers if they choose to do so. The beneficiaries would gain greater control over services provided without having to take on other burdens of self-management such as paying providers or handling tax issues.

A third option is to provide assistance to beneficiaries who wish to assume management tasks. Some counties in California maintain a registry of workers to help beneficiaries locate potential providers. Other consumer-directed programs provide the services of fiscal agents to handle the paperwork and payments associated with managing workers. Finally, programs could be established that enlist beneficiaries who

have been successful in managing their own care to assist others who want to do the same.

Policymakers should not assume, however, that all beneficiaries want to manage their own care. Programs should not impose this requirement on beneficiaries who may be too frail, have too many disabilities, have severe dementia, or have too little management experience to take on these tasks.

Fortunately, a number of demonstrations are underway that will enhance our understanding of the issues that need to be addressed when considering opening up public long-term care programs to consumer-direction. Although these results will not be available for several years, policymakers can take steps now to improve their long-term care systems by using some of the techniques described in this issue brief.

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Table 1: Social Insurance Programs

	Austria (Badelt et al. 1997)	Germany (Runde et al 1996)
Purpose of Research	To determine the effects of the Long-Term Care Allowance on beneficiaries and their caregivers.	To study the impact of the Social Dependency Insurance on beneficiaries.
Sample	1% random, stratified sample of 3,120 beneficiaries living in their homes or communities, and their caregivers.	Simple random sample of 10,400 beneficiaries age 30+.
Survey Method	In May 1995, beneficiaries received 2 mailed surveys, one for them and one for their primary caregivers (paid or unpaid).	In April 1996, beneficiaries received a mailed survey to which they, their caregivers, or both could respond. This survey was the first in a series of three panel surveys.
Respondents	<p>About half of beneficiaries (1,498) and caregivers (1,396) responded. 56% of beneficiaries asked “confidants” to fill out the survey. Another 27% asked caregivers for help.</p> <p>Respondents were representative of program beneficiaries. 75% of respondents were age 70+, 67% were female, 36% lived alone. Up to 85% had limitations in performing certain IADLs, and about 75% had limitations in at least one ADL.</p>	3,359 of the respondents met the study’s criteria; they were representative of program beneficiaries age 30+. Response rate was 31%. 77% of respondents were age 65+, 63% were women, and 35% lived alone. 76% of respondents chose cash assistance, 7% chose services, and 17% chose a combination. Respondents could be beneficiaries themselves or caregivers who responded for them.
Results	<p>Effects of Allowance on beneficiaries:</p> <ul style="list-style-type: none"> • 57% of beneficiaries felt that they were less dependent on unpaid help as a result of cash assistance. • 65% felt that they had more freedom to select their caregivers. 	<ul style="list-style-type: none"> • 64% of respondents felt that the program gave relatives an incentive to provide care. • 88% of respondents felt that one should do everything possible to remain independent.

	<ul style="list-style-type: none"> • 81% felt that they could compensate relatives for care. • 71% felt that they handled daily pressures better. <p>Effects on Caregivers:</p> <ul style="list-style-type: none"> • 74% provided care because they had a familial relationship with the respondent. • 8% said that financial compensation explained part of their motivation for caring for the respondent. • 59% said that cash covered most of their costs for providing care. • 49% said that cash helped them coordinate care better. • 10% reduced work hours and 9% quit their jobs. • 29% used the cash for home modifications. <p>Financial Arrangements from the perspective of beneficiaries:</p> <ul style="list-style-type: none"> • 33% had no financial arrangement with the primary caregiver. • 30% believed cash assistance became part of the common budget. • 24% compensated caregivers for costs incurred. • 25% regularly compensated caregivers. 	<ul style="list-style-type: none"> • 72% of respondents felt that the insurance program was necessary to preserve independence. • 72% of respondents felt that the program was necessary to preserve “beneficiaries rights to self-determination.” • 55% of respondents felt that the care situation had improved as a result of the insurance benefit; only 3% felt it had worsened. • 5% said their care support had been reduced as a result of the insurance benefit. • 35% of respondents said that they used more professional home care services, and 20% reported that they no longer used such services. • 43% of respondents said that quality of care had improved as a result of receiving benefits; 2% said quality had worsened. • 2% of respondents said that beneficiaries were brought home from a nursing facility as a result of the new program. • 85% of cash respondents, 61% of combination respondents, and 27% of agency service respondents felt it was an advantage that they could freely decide how to use their benefits. • 49% of cash respondents, 35% of combination respondents, and 20% of agency service respondents felt it was an advantage that the program provided income for caregivers. • 67% of cash respondents, 42% of combination respondents, and 19% of agency service respondents felt it was a disadvantage that strangers come into the house under service benefits.
Limitations	Many beneficiaries received help from others in filling out the survey. Although unavoidable, answers may have been influenced.	Many beneficiaries received help from others in filling out the survey. Although unavoidable, answers may have been influenced.

Table 2: Non-Means- Tested Demonstration Programs

	France (Gilles et al. 1995; Simon and Martin 1996)	The Netherlands (Miltenburg et al. 1996)
Purpose of Research	To determine the best way to organize long-term care services and to ascertain the number of dependent people and the cost of providing their care.	To determine whether providing “client budgets” is a good alternative to agency services and the effects of such budgets on participants.
Sample	<p>All 4,691 participants in the demonstration project were contacted by mail to determine if they were willing to participate in an in-home survey. 28% refused, had died, or were no longer living in the community by the time the survey was conducted; 4 months elapsed between the mailing and the interviews. The researchers then took a stratified, random sample of the remaining 3,380 participants.</p> <p>This sample yielded 713 participants age 60+ with low incomes. Average age was 80.6, 33% lived alone, 19% were very severely disabled. Survey respondents were from 12 French departments (provinces) chosen for their prior commitment to programs for older persons. Two of the departments provided agency services only, 4 provided cash payments, and 6 a mixture. About 75% of respondents received a cash allowance. All departments giving cash had controls verifying how the money was spent.</p>	<p>The study contacted 2,615 current or future users of home care in two cities and asked them to participate in an evaluation of cash assistance. Children and people with dementia could participate only if they had a surrogate decision maker available. Of those contacted, 1,440 refused to participate for several reasons including: they were satisfied with current services (28%); and they did not want to participate (27%). The final number of participants was 1,066.</p> <p>68% of participants were female, 49% lived alone. Half of the participants needed no assistance with activities of daily living. The typical participant received 15 to 19 hours of <i>informal</i> care a week. The average participant needing home help and nursing care had 7 hours of <i>formal</i> home care a week authorized.</p>
Research/ Analytic Method	Participants were interviewed at home using a standard protocol, with a caregiver to assist if the respondent had difficulty answering questions. 13% were interviewed alone, 74% with a family member, and 13% with an aide.	The 1,066 participants were randomly assigned to one of three groups: one experimental group offering a choice between cash or agency services; a second experimental group offering the same choice with the addition of optional counseling for those choosing cash (only 7% chose counseling); and a control group receiving agency services.

		<p>The cash benefit was set at 100% of the cost of agency services - on average \$635 a month.</p> <p>For analytic purposes those who chose cash in the two experimental groups were combined (n=308). The control group had 361 participants.</p>
<p>Results</p>	<ul style="list-style-type: none"> • 33% of respondents believed that an advantage of the cash benefit was that it provided more control over workers. • 66% of respondents believed that an advantage of agency services was the ability to avoid administrative tasks such as having to advance cash to workers, to visit governmental offices to verify workers' salaries, and to recruit workers. • 30% of aides were family members or friends. • 36% of participants switched aides after receiving the new allowance. • 54% of participants said that the allowance permitted them to hire home help. • 24% said the allowance permitted them to receive financial aid. • 22% said it helped them avoid entering a retirement home. • 5% said their quality of life improved. • 93% of participants were satisfied with their workers. • 64% said that the allowance had improved their lives. 	<p>45% of participants in each experimental group chose cash; 30% of those 75+ in both groups did so. Average age of those choosing cash was 70; it was 74 for those choosing agency services. Common reasons for choosing cash included: getting good help and having more flexibility and greater control over care. Reasons for choosing agency services included long-term relations with an existing agency and difficulty in obtaining care from a trustworthy source. Persons new to home care were significantly more likely to choose cash than others. About 90% of those in the experimental groups would choose cash again.</p> <p>Participants in the experimental and control groups reported some significant differences in perceived quality of care. 67% of those in experimental groups believed their home helpers were efficient vs. 38% of those in the control group. In cases where the participants had more than one worker, 47% of the experimental group participants reported good continuity of care vs. 25% of the control group participants. 85% of those in experimental groups believed they had freedom of choice and control over the care received; only 46% of control group participants felt this way. All of these differences were significant at $p < .02$ or less.</p> <p>Almost all participants used the cash to purchase services. 2/3 of the experimental groups used the cash only to purchase nursing and home care. 25% of the groups said they used the cash for related items such as home modifications and new clothes. 63%</p>

		<p>purchased their services through the private market. 12% paid family members. 90% of participants purchased the care themselves, and the rest relied on others to do so. 80% of the clients reported no trouble in purchasing assistance. 10% reported problems involving continuity of care and tailoring care to their needs.</p> <p>The experimental group participants were able to purchase more services than those in the control group because services purchased in the private market were less expensive than those purchased through an agency.</p>
<p>Limitations</p>	<p>Respondents received assistance from family members and caregivers in responding to questions. Those who refused, died, or could not participate in the survey may have been among the most frail, so their views would not necessarily be reflected in the survey results.</p>	<p>This study has a very sound research design. One issue is the composition of those who refused to participate -- a possible source of bias.</p>

Table 3: Means-Tested Programs in the United States

	California In-Home Supportive Services (IHSS) Program (Benjamin et al. 1998)	Survey of Medicaid Beneficiaries Receiving Personal Care in Maryland, Michigan, and Texas (Taylor et al. 1991)
Purpose of Research	1) To compare outcomes for respondents who managed their own long-term care services (consumer-directed model) to those of respondents who relied upon a home health agency to manage services (agency-directed model). 2) To compare outcomes for respondents in the consumer-directed model who hired family with outcomes of those who hired non-family workers.	To determine how consumer choice affects Medicaid beneficiaries' satisfaction with their lives and their aides.
Sample	<p>Stratified, random sample of IHSS participants who were age 18+, did not have severe cognitive impairment, and who spoke English, Spanish, Cantonese, Mandarin, or Vietnamese. Sample was stratified to obtain roughly equal numbers of beneficiaries: 1) over and under age 65; 2) in consumer-directed (CD) and agency-directed (AD) care; and 3) with moderate and severe disabilities (i.e. needing 20+ hours of service a week). Response rate for the survey was about 78%. Those who refused to participate were older, more likely to be white, and had less severe disabilities than those who responded to the survey.</p> <p>About half of CD and AD respondents were age 65+. CD respondents (n=511) were significantly less likely to be female, less likely to be white, less educated, and less likely to be living alone than AD respondents. 52% of CD respondents had severe disabilities compared to 13% of AD respondents (n=584). Counties are much more likely to assign persons with severe disabilities to the CD model when there is a choice.</p>	<p>879 Medicaid home care beneficiaries in Maryland (n=300), Michigan (n=276), and Texas (n=303). About half of each state's sample was urban and the other half rural. People with severe cognitive impairment were not included. Survey response rates were above 90 percent in each of the three states.</p> <p>80% of respondents were age 70 or over. 87% of respondents were female; 65% lived alone; 64% were on Medicaid for at least 6 years. 14% had trouble performing 4 or 5 ADLs, another 33% had trouble with 2 or 3 ADLs. 79% of respondents had trouble with at least 2 IADLs.</p>

<p>Research/ Analytic Method</p>	<p>Telephone interviews were conducted with 511 CD respondents and 584 AD respondents. The authors used factor analysis to reduce their multiple measures of respondent outcomes to a small number of dimensions — safety, empowerment, unmet needs, satisfaction, and quality of life. The authors used hierarchical regression, in which the researcher chooses the order of introduction of variables into the regression, to analyze the predictors of client outcomes.</p>	<p>In-person interviews were conducted with Medicaid beneficiaries in 3 states. The authors constructed a 5-point index of choice for each beneficiary using 5 factors including whether the beneficiary knew aides before services began, controlled scheduling of services, signed time sheets, hired and fired workers. States were rated on the amount of choice beneficiaries had.</p>
<p>Results</p>	<p>54% of CD respondents considered the number of IHSS hours inadequate compared to 37% of AD respondents; this may be due to the high percentage of CD respondents with severe disabilities. On average, CD respondents had had 3.8 years with the same provider: For AD respondents it was 3 years. 8% of CD respondents needed help finding a provider compared with 46% of AD respondents. 73% of CD respondents knew their providers before hiring them compared with 6% of AD respondents. 62% of CD respondents reported supervising their providers, with the remainder reporting that the providers supervised themselves. 40% of AD respondents reported supervising their workers.</p> <p>In 12 counties where the CD and AD coexisted, the case managers assigned clients to one of the service models. People who were over age 65, white, lived alone, and did not have severe disabilities were more likely to have case managers assign them to AD care.</p> <p>Age was a significant predictor of certain outcomes. Persons over age 65 were significantly less satisfied with their services and choice over them, had fewer unmet IADL needs, had less satisfaction with the effect of provider services, and had higher physical well-being scores than those under age 65.</p> <p>After controlling for such factors as age, service model (i.e., CD, AD) was a significant ($p<.05$) predictor of 6 client outcomes. CD clients reported more</p>	<ul style="list-style-type: none"> • Michigan permitted the most beneficiary choice -- 70% of beneficiaries scored 3, 4, or 5 on the index. Only 25% of beneficiaries did so in Maryland and 21% in Texas. • 59% of those scoring 0 on the choice scale were very satisfied with their aides vs. 90% of those with scores of 4 or 5. • 63% of those scoring 0 said aides are very concerned about their well-being vs. over 90% of those scoring 4 or 5. • 49% of those scoring 0 said their aides came to work as expected vs. over 90% of those scoring 4 or 5. • 51% of those scoring 0 said their aides knew how to get things done very well vs. over 97% of those scoring 4 or 5. • 67% of those scoring 0 said their aides' presence improved the quality of their lives vs. over 90% of those scoring 4 or 5.

	<p>satisfaction with their services and choice over them, stronger preference for the role of managing services, higher technical quality of the care received, greater satisfaction with the effect of provider services, and higher emotional, social, and physical well-being.</p> <p>Provider type within the CD model was a significant predictor of 4 client outcomes. Clients with family providers reported a higher sense of security, more satisfaction with their services and choice over them, stronger preference for the role of managing services, and satisfaction with the providers' interpersonal manner than clients with non-family providers.</p>	
Limitations	The study excluded clients with cognitive impairment.	The study excluded clients with cognitive impairment.

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