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**CONSUMER-DIRECTED HOME CARE IN THE
NETHERLANDS, ENGLAND, AND GERMANY**

by

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FOREWORD

Persons with disabilities of many ages, including older persons, strongly prefer independent living in their own homes to other alternatives. In addition, consumers want more direct control over long-term supportive services they receive. In many U.S. states, options for consumer-directed services in Medicaid or state-funded programs have been increasing, and debate about the pros and cons of consumer-direction is an increasingly prominent part of policy discussions at both the state and federal levels. While most of the discussion in the U.S. has focused on increasing choice in means-tested programs in the states, consumer-direction is also relevant to a social insurance approach to financing long-term care, as is found in a number of other developed nations.

Many other nations permit persons with disabilities to choose a consumer-directed home care option, often through cash payments that vary with the level of disability. Among these countries are Austria, Germany, the Netherlands, Italy, and the United Kingdom. These programs vary widely in size and structure, including eligibility criteria, administration, financing, and quality monitoring

In order to gain a better understanding of how consumer-directed programs abroad have evolved, AARP's Public Policy Institute commissioned Joshua Wiener, Jane Tilly, and Alison Evans Cuellar to closely examine the experiences of three countries. The countries, the Netherlands, England, and Germany, were selected because of the diverse structures of their programs and the different ways they "fit" into the larger long-term care systems in each nation.

This report provides a wealth of descriptive detail about the programs in each country, along with a comparative overview that also draws out the implications of the findings for the U.S. Country case studies include the most current information available on the cost and use of consumer-directed services, and assess both the strengths and weaknesses of the programs.

This report tackles some of the most complex and controversial issues in consumer-direction, including how costs are contained, how quality is monitored, and what protections home care workers receive. It is our hope that it will be timely and useful to policy makers in the U.S. and abroad, to consumer advocates, and to others as they evaluate ways to enhance independence, dignity, and quality of life among persons with disabilities of all ages.

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EXECUTIVE SUMMARY

Background

A key issue in the design of home and community services programs is the extent to which clients control their services. Traditional publicly-funded home care programs rely on public or private agencies that are responsible for hiring and firing home care workers, scheduling and directing services, monitoring quality of care, disciplining workers if necessary, and paying workers and applicable payroll taxes. In this agency-directed model, clients can express preferences for services or workers but have no formal control over them.

A major innovation in long-term care in the United States and Europe is the development of publicly funded, consumer-directed home care. These programs, which represent the other end of the management continuum, give consumers, rather than home care agencies, control over who provides services, when they are provided, and how these services are delivered. Typically, consumer-directed programs allow the consumer to hire, train, supervise, and fire the home care worker. In some programs, beneficiaries receive cash payments enabling them to purchase the services they want.

Purpose

The purpose of this study is to describe and analyze publicly funded, consumer-directed home care programs in the Netherlands, England, and Germany, and to draw implications for the long-term care system in the United States.

Methods

Information for this study was obtained from two sources. First, government officials, researchers, and representatives of provider and consumer groups were interviewed in-person during site visits that were conducted in each of these nations during fall 2002. About 15 interviews were conducted in each nation. Second, the interviews were supplemented by newspaper and journal articles, government documents, and provider, consumer, and research publications, which were obtained both in hard copy and through a search of Internet websites.

Principal Findings

Germany and the Netherlands primarily fund long-term care services through non-means-tested social insurance programs financed by national premiums. The programs cover a broad range of institutional and noninstitutional services. While Germany's program (*Soziale Pflegeversicherung*) is relatively recent, dating only to 1995, the insurance system in the Netherlands (*Algemene Wet Bijzondere Ziektekosten, AWBZ*) began in 1968. In contrast, consumer-directed home care in England is primarily funded through means-tested programs designed and operated by local governments, albeit largely with funds provided by the national government.

Consumers in the three countries have a choice between agency-directed and consumer-directed home care. In the Netherlands and England, the overwhelming majority of community-based beneficiaries receive agency-directed care, although use of consumer-directed care is growing. In Germany, the overwhelming majority of noninstitutional beneficiaries opt for consumer-directed care.

The countries differ in how they structure their consumer-directed options. In the Netherlands and England, clients are provided funds (“personal budgets” in the Netherlands and “Direct Payments” in England) that they must use for home and community services. In Germany, clients receive cash payments, based on their level of disability, that they may spend on anything they like. In Germany, the cash payments are mostly used to support informal caregivers.

Contrary to the expectations of some observers, consumer-directed home care in the three countries is used by older as well as younger persons with disabilities (although less so in England) and by people with severe as well as mild disabilities. Indeed, in all three countries, the Netherlands, Germany, and England, some cognitively impaired persons participate in these programs, relying on surrogates to make decisions for the consumers.

Given the concern of some observers about the management capability of people with disabilities to handle management tasks, it is somewhat surprising that the three countries provide only modest assistance to help clients cope with the administrative tasks inherent in consumer direction, leaving clients mostly to find their own way. Programs in the Netherlands and England provide the most help with handling social insurance and other taxes and paying the worker; however, since few people are formally “hired” in the German system of cash payments, very little formal assistance is provided through the cash payment mechanism.

Labor force issues are a major component of the dynamics of consumer-directed home care. Reflecting the more developed social protections in European countries, consumer-directed home care workers have higher wages and far better fringe benefits than similar workers do in the United States. These fringe benefits improve the workers’ lives but add significantly to the cost of services. Despite these advantages, all three countries have experienced a shortage of long-term care workers, as we have in the United States. Especially in the Netherlands, growth in consumer-directed home care (and the use of family caregivers) is, in part, a frustrated response to the waiting lists for agency-provided care.

While much of the policy interest in consumer-directed home care derives from a desire to empower people with disabilities and give them more control over their lives, this approach is also attractive to governments because of its lower per person costs. Payment rates for consumer-directed care are much lower than for agency care, partly because there is little or no administrative overhead, which can be substantial for agencies. Moreover, while independent workers in these countries are compensated far better than American workers, they tend to do less well financially than at least a significant segment of agency workers.

Probably the most contentious issues in the United States surrounding consumer-directed programs relate to whether quality of care is adequate and how services should be monitored.

Compared with agency-directed care, consumer-directed services lack the standard quality assurance structures of training of paraprofessionals, supervision by professionals, and provision of technical services by professionals. Despite some concerns about quality of services, the three countries have taken minimalist approaches to monitoring quality. In place of formal quality assurance mechanisms, consumer-directed programs rely on clients' ability to fire unsatisfactory workers and to hire replacements to assure quality—in other words, the market. In addition, at least in Germany and the Netherlands, policy maker are relying on the strength of family ties and the notion that relatives are much more likely than strangers to provide high-quality care.

A major worker-related issue is that a very significant portion of independent workers are family members in every country but England. Many of the issues discussed above—management, training, quality assurance, and payment levels—take on a very different cast if the independent provider is a family member or friend rather than a stranger. The adage, “blood is thicker than water,” may account for some of the countries' relatively laissez-faire approaches to program management.

The use of informal caregivers also illustrates the conflict between equity and efficiency. For example, Germany's cash payments can be justified on an equity basis in that they make family caregivers better off. On moral grounds, policy makers want to reward informal caregivers for their sacrifices; but from an efficiency perspective, the insurance funds are spending a great deal of money without causing a large change in behavior. Extensive informal care is being provided now in Germany—just as it was before the cash benefit was introduced. For people receiving the cash benefit, it is not clear that much has changed, although some observers think it is too early to tell.

Conclusions

The notion of consumer-directed home care challenges the protective nature of most home and community services programs for older people by asserting that clients want to and are capable of managing their own care. The experiences of the Netherlands, England and Germany suggest that these countries are moving ahead successfully in changing the nature of noninstitutional services in a way that gives people with disabilities more control over the services that are so important in their lives.

Consumer-Directed Home Care in the Netherlands, England, and Germany

OVERVIEW

A key issue in the design of home and community services programs is the extent to which clients control their services. Traditional government-sponsored home care programs rely on public or private agencies that are responsible for hiring and firing home care workers, scheduling and directing services, monitoring quality of care, disciplining workers if necessary, and paying workers and applicable payroll taxes. In this agency-directed model, clients can express preferences for services or workers but have no formal control over them. This model operates from the assumption that professional expertise and accountability are critical to providing good-quality and reasonable-cost care. At its extreme, a “medical model” is imposed, and individuals with disabilities are considered to be “sick,” as opposed to simply needing compensatory services, such as help with bathing.¹

A major innovation in long-term care in the United States and Europe is the development of publicly-funded, consumer-directed home care. These programs, which represent the other end of the management continuum, give consumers, rather than home care agencies, control over who provides services, when they are provided, and how these services are delivered. Typically, consumer-directed programs allow the consumer to hire, train, supervise, and fire the home care worker. In some programs, beneficiaries receive cash payments enabling them to purchase the services they want.

In many countries, advocacy for consumer-directed services began with younger people with disabilities demanding the right to manage their own services in home and community settings as a way to become part of mainstream society. The disability movement rejects what they see as paternalistic perceptions that persons with disabilities are vulnerable and need protection and contends that people with disabilities have the ability and the right to make the decisions that affect their lives.²

Consumer-directed home care has slowly become an international policy trend. A number of countries, including France, the Netherlands, England and the rest of the United Kingdom, Austria, and Germany, have implemented programs to give beneficiaries more control over their home care services.³ In addition, a growing number of American states are incorporating consumer direction into their home care programs, including California, Michigan, Oregon, Washington, and Wisconsin.⁴ Moreover, the U.S. Department of Health and Human Services and The Robert Wood Johnson Foundation are sponsoring “cash and counseling” demonstrations in Florida, Arkansas, and New Jersey, where Medicaid beneficiaries of all ages are being given the opportunity to receive cash rather than service benefits.⁵

In the United States, consumer-directed home care is most commonly offered as part of Medicaid personal care, either through the regular optional benefit or through home and community-based services waivers.⁶ In only a few states, including the ones listed above, do a substantial proportion of home care beneficiaries use consumer-directed services. In these programs, clients typically may choose their personal care attendant, but they do not have a

budget they can use to purchase other services. Provision of cash benefits outside of research and demonstration projects is generally not allowed because of legislative requirements and fear of fraud and abuse. Payment of providers and associated Social Security, Medicare, income, and other taxes is almost always done through a fiscal intermediary rather than by the client directly.

Beneficiaries are most often younger people with disabilities, rather than older people, although use by elderly persons with disabilities is significant in states where consumer-directed services are part of the mainstream provision of care. Contrary to the expectations of some, many people with severe disabilities participate in this option, including those with cognitive impairments, often with the help of surrogate decision makers.

Typically, in the United States, independent providers in this option are paid minimum wage and receive few fringe benefits, which make recruitment and retention difficult. In most states offering consumer-directed home care, clients may hire their relatives, with the exception of parents and spouses, who are an important source of workers. States control expenditures by limiting the number of beneficiaries, which is allowed in home and community-based services waivers, and by keeping payment rates low. In general, state quality assurance mechanisms are minimal, with the individual consumer responsible for supervising the services the worker provides.

This project adds to the policy debate by analyzing the experience with consumer-directed home care in three European countries—the Netherlands, England, and Germany. Each of the four nations within the United Kingdom, including England, has developed a different approach to implementing Direct Payments. England, however, was selected for this study because some of its local authorities have a long history of permitting consumer direction, under certain circumstances. This overview compares the three countries across a number of dimensions to address how they have answered seven broad questions: First, how is the consumer-directed home care option structured? In particular, how is the payment level calculated, how widely used is this type of care, and what, if any, restrictions are there on how the money is used? Second, how is the program administered, and what is the role of the consumer? A major issue is the tension between giving consumers control over the benefit versus providing protections to workers.

Third, what types of beneficiaries use this option? Of special interest is whether people with more severe disabilities are allowed to participate, or is this benefit restricted to persons with mild disabilities. Fourth, who are the service providers? A key parameter is the extent to which informal caregivers provide these services rather than persons found in the marketplace. Fifth, what is the level of compensation, in both wages and fringe benefits? Does a higher compensation structure solve the labor shortage problem? Sixth, how does each country control long-term care expenditures, both generally and within consumer-directed home care? Is this approach part of the cost problem or part of the cost solution? And, seventh and finally, how is an adequate quality of care assured? What is government's role as opposed to the role of individual consumers? Detailed descriptions of the consumer-directed home care programs in each country are included in case studies in the Appendix.

Methods

Information for this study was obtained from two sources. First, government officials, researchers, and representatives of provider and consumer groups were interviewed during in-person site visits conducted in the three countries during fall 2002. These in-person interviews were supplemented by telephone interviews in some cases. Respondents were interviewed using an open-ended, semistructured interview protocol. About 15 interviews were conducted in each country; a listing of the number of interviewees by category is available from the authors. To encourage candor, especially from government officials, interviewees were told they would not be quoted by name or listed as respondents. Second, interviews were supplemented by reviews of newspaper and journal articles, government documents, and provider, consumer, and research publications, which were obtained both in hard copy and through a search of Internet websites. Individual country reports were reviewed for accuracy by experts knowledgeable about long-term care in each nation.

Background

The Netherlands, England, and Germany are aging societies with well-developed health, long-term care, welfare, and social service systems. All three countries have an older population than the United States. In 2000, the proportion of the population that was age 65 and older in the Netherlands, England, and Germany was 13.6 percent, 15.9 percent, and 17.3 percent, respectively, compared to 12.4 percent in the United States.⁷ In general, services are often means-tested (that is, only available to persons with income and resources below a certain level) in England (the Beveridge model), in contrast to Germany and the Netherlands (the Bismark model), where services are more often available on a universal, insurance basis.

Unlike the United States, universal coverage for health and long-term care is provided for people of all ages in all three countries. In England, acute care and some long-term care services are provided through the National Health Service, a tax-financed system of physicians and public hospitals. Germany and the Netherlands provide acute care coverage primarily through “sickness funds,” nongovernment insurers heavily regulated by the national government.⁸ In both countries, upper-income persons obtain acute care coverage mostly from private insurers.

For long-term care, Germany and the Netherlands primarily fund services through non-means-tested social insurance programs financed by income-related premiums levied on payroll.⁹ The programs cover a broad range of institutional and noninstitutional services. While Germany’s program (*Soziale Pflegeversicherung*) is relatively recent, dating only to 1995, the insurance system in the Netherlands (*Algemene Wet Bijzondere Ziektekosten, AWBZ*) began in 1968. Eligibility for both programs includes persons of all ages; in the Dutch system persons with relatively modest disabilities are eligible, while the German program is limited to persons with relatively severe disabilities (roughly problems with two or more activities of daily living and some additional instrumental activities of daily living needs). While both countries have insurance systems, until recently the Dutch system was budgeted very strictly. As a result, waiting lists for services are common in that country, although supply constraints rather than budget shortages are the primary reason at this time.¹⁰ Currently, these programs are technically open-ended entitlement programs, although both face financial constraints. The emphasis on

insurance principles, with defined benefits and eligibility, means there is a strong preference for uniform national standards and practices; local variation is frowned upon. Services are mostly provided by private, nonprofit agencies, although there has been an increase in for-profit home care agencies and nursing homes in recent years.

The system is very different in England. Personal care and other nonskilled services are means-tested in most local authorities in England. Home and community care in England has three major components. First, the National Health Service provides some medically related long-term care, including nursing, physical and occupational therapy, and long-term hospital care, which is free of charge to permanent residents. Local health authorities administer these services. Second, England has three major national-level cash allowances designed to help disabled people fund their care expenses.¹¹ The national Department of Work and Pensions manages most of these disability allowances.

Third, most long-term care, including “community care” (for example, personal care and homemaker services), is the responsibility of “local authorities,” which vary greatly in geographic and population size. Although programs are administered at the local level, funding comes primarily from the national government, and the Department of Health provides some national guidance and oversight. Because of the emphasis on local control, there are wide variations in eligibility, spending, availability of services, and cost sharing. Some observers view this as a way of meeting the needs and preferences of local areas, while other commentators are concerned about the lack of horizontal equity across geographic areas. In addition, while there has been great growth in nongovernment, mostly for-profit, home care agencies and residential providers, many local authorities operate public nursing homes and home care agencies.

Findings

The Home Care Benefit: Traditional Services and Consumer-Directed Care

In the Netherlands, England, and Germany, a substantial amount of home care is available, and there is an explicit policy preference for home and community services over institutional care. Consumers in these three countries have a choice between agency-directed and consumer-directed home care, although those choices have been constrained until recently, by either budgets or policy. In the Netherlands and England, the overwhelming majority of community-based beneficiaries receive agency-directed care, while in Germany, the overwhelming majority of beneficiaries living in the community opt for consumer-directed care.

Policy makers in the Netherlands, Germany, and England have five goals in introducing consumer-directed home care into their long-term care systems.¹² First, personal budgets, Direct Payments, and cash payments are all consistent with the notion of making the system more “demand-driven” rather than “supply-driven.” The main goal is to empower consumers and increase independence by giving participants more control over their care. A related concern is increasing integration of people with disabilities into the community. Second, consumer-directed home care, especially cash payments, gives consumers the flexibility to choose those services that best fit their needs. Third, by providing an alternative source of care and increasing

competition, it is hoped that providers will be more responsive to consumer needs. Fourth, an additional goal is to help control the overall rate of increase in expenditures. Because of the way personal budgets in the Netherlands and cash payments in Germany are constructed, this approach costs less than agency-provided services on an individual basis. Finally, providing support for informal caregivers, which is particularly important in Germany, is a final goal of consumer-directed home care.

Chart 1 summarizes the main characteristics of consumer-directed home care in the Netherlands, England, Germany and the United States.

The Netherlands

In the Netherlands, after determination of eligibility by the local assessment office, individuals have the choice of receiving services from an agency or consumer-directed home care, called “personal budgets.” Under personal budgets, an individual is allocated an amount of money—a budget—that he or she can use to buy services from independent providers or agencies. In the Netherlands, budgetholders are legally required to spend their funds only on AWBZ-covered services, and this requirement is monitored closely. Budgetholders may purchase services from independent providers, family members, or agencies.

Starting in April 2003, a new reform is being phased in that will substantially alter the design and administration of personal budgets. Under the old system, separate “personal budget” programs were established for nursing and home care, for persons with developmental disabilities, for persons with mental illness, for persons with physical handicaps needing large amounts of personal assistance, and for persons needing intensive home care benefits (which is designed primarily for end-of-life care). In the new system, these separate programs will be merged into one program.

The level of the personal budget for home and nursing services is determined by multiplying the number of hours needed for each service times the national average payment rate for those services and then reducing that amount by 25 percent and an income-related copayment. There are no adjustments for local variations in cost. In determining the number of hours of services needed, availability of informal care is taken into account, a practice that is strongly opposed by consumer advocates.

The 25 percent reduction in the budget is designed to account for the fact that independent providers do not have the overhead costs that agencies incur. While people receiving services from agencies are billed for and actually pay the copayment, personal budgetholders almost universally treat the copayment as a further discount to their budget allocation and do not pay an additional amount when they purchase a service. There is a budget ceiling of 300 Euros per day, which is the high end of the cost of nursing home care; consumer groups generally oppose the ceiling as being arbitrary.

Chart 1. Characteristics of Consumer-Directed Home Care Programs in the Netherlands, the United Kingdom, Germany and the United States

	England	Germany	The Netherlands	United States
Percent of population age 65+ (2000)	15.9% (United Kingdom)	17.3%	13.6%	12.4%
Functional eligibility	Standards determined locally; generally persons with severe disabilities are eligible.	Need for assistance with 2 ADLs and some IADLs.	Need for help with ADLs or IADLs.	Need for assistance with ADLs and IADLs.
Financial eligibility	Standards determined locally. Most localities means-test benefits using income and asset tests.	Non-means-tested.	Non-means-tested.	Mostly Medicaid rules, which have an income test, an asset test, estate recovery and asset transfer rules.
Number of beneficiaries (all ages)	7,882 people were Direct Payments users in 2002; about 13 percent were aged 65 and older.	1.2 million beneficiaries in 2001 (cash only and cash and services combined).	44,000 beneficiaries in September 2002.	Ranges from about 4,000 to 200,000 per program.
Percent of home care beneficiaries of all ages using consumer-directed care	2% (2002)	73% cash, 12% combination cash and services (2001).	10% (2002)	Not available.
Services covered	No national standards. Generally users purchase help with daily activities from individual workers.	Any services desired.	Primarily assistance with ADLs and IADLs. Small amount of benefit set aside for flexible use. Must be used for social insurance-covered services.	Primarily assistance with ADLs and IADLs.
Benefit amounts	Generally, localities multiply the number of hours of services users need by an hourly amount that is designed to cover worker wages and overhead such as taxes.	3 benefit levels based on severity of disability. Beneficiaries choosing cash receive 40-50% of the value of services benefits. Benefits are not indexed for inflation.	Hours of care needed are multiplied by national, standard payment rates to home care agencies to determine the benefit level. Deductions taken for lack of administrative overhead by independent and income-related copayments.	States limit hours of care or set dollar limits on benefits. Two states have no benefit limits.

	England	Germany	The Netherlands	United States
Funding sources	Fixed amount of general revenue from the national government that is earmarked broadly for social services. Localities determine the amount devoted to Community Care.	1.7% of salaries and pensions shared by employees and employers, and retirees and pension funds, respectively.	Worker paid, income-related insurance premiums; 10.25% of wages for lower tax brackets.	Generally, states use Medicaid and state-only funds.
Possible to hire a relative	Generally no, although some exceptions are made under special circumstances.	Yes, but rarely formally “hired,” although funds mostly used to support informal caregivers.	Yes, including spouses and parents.	Yes, but most states prohibit hiring spouses.
Quality assurance	Users are responsible for quality assurance but case managers have periodic contact with clients.	Periodic visits to determine that cash beneficiaries are receiving adequate care.	Budget holders have a legal obligation to obtain good-quality care.	All states monitor quality in some manner, but requirements are not extensive.

Notes:

1. US data are Jane Tilly and Joshua M. Wiener, “Consumer-Directed Home and Community Services Programs in Eight States: Policy Issues for Older People and Government,” *Journal of Aging and Social Policy*, 12(4): 1-26, 2001; data is for 1999.
2. ADLs are activities of daily living, which include such tasks as eating, bathing, and dressing. IADLs are instrumental activities of daily living, which include such tasks as shopping, preparing meals, using the telephone, and medication management.
3. Population data from the Organization for Economic Co-operation and Development and the U.S. Bureau of the Census.

Until recently, the national government allocated only a small level of expenditures to consumer-directed personal budgets—3 to 5 percent—of home care expenditures. With the switch from a budgeted to an open-ended entitlement system, use of personal budgets has been increasing rapidly, in part because of waiting lists for agency-directed services. By September 2002, more than 44,000 persons, about 10 percent of home care beneficiaries, were personal budgetholders.

England

In England, publicly-funded community care is typically available from agencies run by local authorities or by private, for-profit agencies. Availability of consumer-directed home care, called “Direct Payments,” is a recent policy development. It has been offered to younger adults with disabilities only since 1997, and to older people, disabled children age 16 and 17, parents of disabled children, and persons with developmental disabilities since 2000. Disability criteria vary substantially across local authorities, as do financial eligibility criteria.

Based on the local authority’s assessment of need, which takes into account availability of informal care, case managers generally list the services a user needs and translate these tasks into hours of service per day. The locality attaches a monetary value to these services for persons who choose Direct Payments. The monetary value must be sufficient to enable the user to legally secure services of adequate quality. Localities also generally add money for overhead related to the costs of employer taxes, four weeks’ paid holidays, sick pay, recruitment, and training costs. Case managers then refer users to a Direct Payments support program if one is available locally. Although there is no nationally determined specific maximum budget amount, stakeholders say that Direct Payments for home care are not supposed to exceed the cost of residential care. There can be large disparities in budgets across geographic areas and age groups. Most local authorities impose some income-related copayment, and there is usually a means test.¹³ As in the Netherlands, use of the Direct Payments is limited to authorized services and is monitored quite closely.

In addition to direct services to persons with disabilities, all informal caregivers (“carers”) are entitled to local authority assessments of their need for supportive services, but localities have no obligation to provide services to this population. When local authorities do provide services, carers can choose Direct Payments or vouchers. When carers receive a voucher, they can only buy services that help them provide care to the disabled person (for example, mobile telephones, transportation). Neither Direct Payments nor vouchers can be used to pay for hands-on services for the disabled person, since those services must be part of the disabled person’s service plan. This restriction was imposed so that the disabled person maintains control over his or her own services. According to advocacy groups, however, only a minority of localities provide the services the carers’ assessments say are needed. The national government also funds an additional caregiver supports program, which is implemented at the local authority level.

Although Direct Payments in England have been technically available since 1997, at least for the younger population with disabilities, take-up has been extremely slow. According to Department of Health figures, by fall 2002, 7,882 people were Direct Payment users; only 1,032

of these were age 65 and older.¹⁴ The number of such users with developmental disabilities was 736; the number of people with mental health conditions was 132. Most users were people with physical disabilities. Although they are becoming more available, Direct Payments remain an extremely small part of the home care service system, accounting for only about 2 percent of community care clients.

Germany

In Germany, after determination of threshold eligibility by the medical offices of their sickness fund, applicants are placed in one of three disability categories—substantial disability, severe disability, and very severe disability—each of which is associated with a fixed maximum level of home and community and institutional benefits.¹⁵ The availability of informal care plays no role in the decision about level of benefits; to do otherwise is thought to be inequitable and to violate insurance principles. When applying for benefits, clients select either institutional or home care.

Within home care, clients have a choice of spending up to a set amount on services or receiving a lower fixed amount of cash, roughly 40 percent to 50 percent of the cost of the maximum service benefit. Cash benefits range from 205 Euros a month for substantial disability to 665 Euros a month for very severe disability. To be eligible for the cash benefit, care must be “secured,” that is, some system of caregiving must be in place, but few persons are ever turned down. In addition, any beneficiaries who require significant general supervision due to mental or developmental impairment may receive an additional flat amount, which is independent of their disability level or whether they choose cash or services, to be used for specific services geared to providing respite to caregivers.

In 2001, 50 percent of all long-term care insurance beneficiaries (962,100) chose the cash benefit, 8 percent chose the combination of cash and services, 9 percent chose formal agency-directed home care and related services, and 30 percent chose institutional care.¹⁶ Since the program’s inception, there has been slow but steady growth in the proportion of people choosing a combination of cash and formal home care services. While half of beneficiaries choose the cash option, the benefit accounts for only 25 percent of total program expenditures because the per person cash benefit is set at only 40 percent to 50 percent of the maximum allowable expenditure for agency services.

In Germany, there is no requirement that funds be used to buy long-term care services, nor do beneficiaries have to report how the funds are spent. Consequently, government officials do not worry about the benefit being “misused.” The main intent of the benefit is to promote care at home and to support family caregiving. Officials view the cash payment as being more like a social security benefit under which it would be inappropriate to strictly monitor how beneficiaries spent their money.

Administration

Administration of long-term care generally, and the consumer-directed home care option, varies from quite complicated to relatively simple. In general, administration is quite complex in

the Netherlands and a bit less so in England; it is fairly straightforward in Germany, at least after eligibility is determined. Much of the complexity in England and the Netherlands is derived from constraints put on beneficiaries regarding how they spend their money and from efforts to protect workers and provide them with the social benefits to which they are entitled.

The Netherlands

Administration of the long-term care system in the Netherlands is very complicated, and its complexity has been a major policy issue, especially as it relates to personal budgets. In interviews, the system was almost universally characterized as bureaucratic and cumbersome, with too many layers and too many decision makers. Several major changes over time in how management personal budgets are managed have added to the instability of administration. The new system implemented in April 2003 seeks to simplify matters but will shift much of the administrative burden onto consumers and workers.

In 1998, the Netherlands created a single point-of-entry system for all long-term care services that is responsible for doing client assessments and initial care planning.¹⁷ The new system will completely revamp the assessment methodology, with much more emphasis on detailed functional needs rather than on traditional service categories. Under both the previous and new system, if a client chooses a personal budget, that information is sent to regional health care offices for approval or modification of the proposed budget. Calculations of the individual provider payment rates on which the budgets are based are done by a separate organization.¹⁸

At the time of the site visit, the Social Insurance Bank (SVB), which is in charge of paying beneficiaries of several pension schemes, was responsible for most of the financial management of personal budgets.¹⁹ Under the new system, the money will go directly to the budgetholders, and most of the SVB's administrative functions will be transferred to the consumer, including paying their workers and other providers. The budgetholders themselves will receive periodic disbursements of their funds based on the size of their budget. The burden on consumers, but not independent providers, will be reduced by the requirement that workers employed by an individual for two days a week or less are responsible for making their own social insurance and other tax payments. It is estimated that all but 5 percent to 10 percent of budgetholders have workers in this category. The small minority who are responsible for social insurance and other tax payments will be able to continue to have the SVB handle these payments at no charge to the beneficiary. Others may contract with another agency for those tasks. Regional health care offices will be responsible for approving payments made by the budgetholders after the fact. Individuals who make payments for uncovered services will be subject to cost-recoupment efforts through reductions in prospective budget allocations, retrospective recovery of payments, or suspension from the personal budget option.

England

In England, the local authorities are responsible for the administrative aspects of community care and Direct Payments, so the process varies substantially. Initial assessment and case management are conducted by social workers and nurses of local departments of social services. Until recently, local social service authorities had few requirements regarding their

assessments; recent national guidance requires a single set of assessments for older people, with the intensity of assessment related to level of disability. For Direct Payments, case managers develop a service plan and calculate its cost. Most localities require Direct Payment users to set up separate bank accounts for their payments that localities can audit. Workers typically fill out time sheets documenting their provision of services, which users sign. Some, but not all, local authorities have support centers to aid clients with the administrative requirements of paying workers and handling taxes.

Germany

In Germany, client assessments are conducted by the medical offices of the sickness funds, with the average eligibility determination taking two months to complete.²⁰ Although most consumers are satisfied with the process, a significant minority believe they should have been placed into a more disabled category (with higher benefits), and some beneficiaries complain the assessment is overly standardized and does not take their specific needs into account.²¹ Consumers receive little help from sickness funds in choosing between cash and services or in developing a care plan, although a new law requires sickness funds to do more. All providers seeking reimbursement from sickness funds must have a contract with the funds. Provider reimbursement rates are negotiated with the sickness funds, either on an individual level or as part of a collective agreement. The vast majority of consumers who choose the cash benefit use those funds for household expenses (often with an informal caregiver) or give the money to an informal caregiver rather than “hire” people to provide services or purchase services from agencies.

Beneficiaries

One of the threshold issues for consumer-directed services is whether people with disabilities, especially older people and people with severe disabilities, want to take on these management responsibilities, whether they are capable of doing so, and whether they will be allowed to do so. In all three countries, people of all ages and with a wide range of disabilities participated in the consumer-directed option, although participation by older people in England is quite limited, so far.

The Netherlands

In the Netherlands, many stakeholders expect the proportion of home care beneficiaries who will choose personal budgets will continue to grow and then level out at about 20 percent of total home care users. Although chosen by only a minority of beneficiaries, personal budgets are used by persons of all ages and with all types of disabilities. Because program eligibility requirements do not limit services to people with severe disabilities, many personal budgetholders have relatively low levels of disability, needing only housekeeping services; thus, managing these services may not be overly complex.

When clients have Alzheimer’s disease, a stroke, or other mental health issues or impairments, family and friends make most of the decisions. Among persons with developmental disabilities, personal budgetholders tend to be those with younger, relatively

assertive parents. The use of surrogate decision makers raises a number of issues about the ability and willingness of proxies to reflect individual consumers' desires.

A number of organizations help budgetholders to negotiate the system on a case-by-case basis, especially in terms of hiring workers. But there are limited mechanisms to address systemwide issues such as shortage of workers, training workers and consumers, managing paid caregivers, establishing backup systems in case of illness or other absences, and other issues. Per Saldo, the organization of budgetholders, informs, advises, and supports budgetholders and represents their interests in the political and policy process.²² Like many other interest groups in the Netherlands, Per Saldo is supported largely with government funds.

England

Use of Direct Payments has also been limited, in part, because it has been offered only at the option of individual local authorities, which have been reluctant to make it a major priority. Initially in England, the national government did not require localities to offer Direct Payments, but slow take-up caused it to reconsider this issue. In an August 2002 policy change, the national government mandated that Direct Payments be offered as an option to beneficiaries. Slow adoption is attributed to numerous factors, including fear on the part of local authorities that demand will overwhelm the resources localities allocate to community care; lack of education about this option; and a protective attitude on the part of some local governments toward people with disabilities, particularly those who are elderly, frail, or have some type of mental disability.²³ In particular, few older people seem to know about Direct Payments. In addition, understaffing and competing demands in other sectors at the local authority level have contributed to the lack of implementation of programs such as Direct Payments. According to some observers, many localities simply do not have the infrastructure necessary to implement new programs aggressively. Users of the consumer-directed option in England must be able to manage the Direct Payment either alone or with assistance. Assistance can involve someone with power of attorney, a carer, or some other third party who helps the user with his or her responsibilities as an employer.

According to interviewees, other barriers affect take up of Direct Payments among minority populations in England.²⁴ For example, many minorities may not speak English as their first language, and translating Direct Payment materials into other languages can slow enrollment. In addition, some cultures discourage hiring women to provide personal assistance.

Germany

In Germany, the cash option is by far the most common preference for virtually all groups and all levels of disability. In 1998, 82 percent of long-term care insurance beneficiaries at the substantial disability level chose cash, compared to 77 percent of people at the severe disability level, and 64 percent at the very severe disability level.²⁵ Those beneficiaries who elect the cash benefit tend to be somewhat less disabled, younger, have a spouse or child as caregiver, and have more support (formal and informal) available to them than persons who elect the service benefit.²⁶ Persons living alone were only somewhat less likely (by seven percentage points) to choose cash than were all beneficiaries living at home. In part, this reflects the fact

that persons living alone at home are less disabled and less likely to have mental disorders than the average beneficiary.

Dementia or other mental disability is not a reason to deny cash payments, although in such cases the cash benefit may not be paid directly to the beneficiary. Some beneficiaries may have a designated legal representative who manages their affairs and receives funds on their behalf.²⁷ In many cases, this representative is a family member.

According to national survey data, 88 percent of German consumers who elect cash payments say they do so because it is needed for ongoing long-term care costs; 87 percent say they prefer to receive care from family and friends rather than from strangers.²⁸ Beneficiaries rarely indicated they had to choose informal care because professional services were not available locally. In the same survey, 90 percent of those choosing services responded that the poor health of the beneficiary made professional services unavoidable, or that services were recommended by the medical office. Fully 73 percent of service-user respondents said that informal caregivers were overburdened, and 65 percent reported they did not wish to burden their caregivers even more.

A separate study in one local area found the most important reasons for persons electing service benefits over cash benefits were that family or friends were becoming too burdened and more professional services were needed.²⁹ However, those choosing service benefits reported having more difficulties organizing their care and having their needs taken seriously than persons electing the cash benefit. In contrast, those beneficiaries choosing cash benefits said the most important reasons were to obtain assistance that met individual needs (49 percent), to control their own services (35 percent), to avoid having strangers in their home (25 percent), and to be able to pay informal caregivers already in place (24 percent).

Service Providers under Consumer-Directed Home Care

In all three countries, consumer-directed home care participants use a combination of independent contractors, including relatives and other informal caregivers, and agencies to provide services. In the majority of cases, however, participants rely on independent contractors.

The Netherlands

In the Netherlands, about 70 percent of budgetholders pay informal caregivers or other independent providers, and about 30 percent use agencies, mostly newer for-profit firms.³⁰ Informal caregivers play a major role in consumer-directed home care in the Netherlands; about half of all budgetholders pay informal caregivers. While there is some concern about paying for services that are already provided for free, and that paying informal caregivers can trap women in low-wage jobs with no job advancement possibilities, the notion of paying family members, including spouses and parents, is widely accepted. Reportedly, budgetholders are relieved at being able to pay something to their informal caregivers to offset the burden their care imposes. Older people are more likely to choose relatives as their service providers than are younger people with disabilities. Hiring parents, spouses, and other close relatives complicates

accountability because these persons also have a lot to say about the services the client receives and who will provide them.

Among younger persons with physical disabilities, most budgetholders tend to hire friends or an individual worker not previously known to the client rather than family members. Their first choice is not to hire relatives, but clients sometimes must do so because of the shortage of workers. Aside from informal caregivers and friends, consumers find workers through advertisements, notices on church bulletin boards, and a website run by Per Saldo, the consumer organization of budgetholders. In at least one early study of the program, approximately 50 percent of individual care providers employed by budgetholders did not have paid work before they took these jobs.³¹

For home care agencies, providing services to budgetholders is a way of earning additional money, but staffing shortages limit the amount of services they can provide. For agencies, contracting with personal budgetholders entails a level of risk they do not have under the services-in-kind system—under the new system, they have contracts with individual clients who may not pay their bills on time or may cancel contracts. In general, formal home care agencies already believe their payment rates are too low, so they are reluctant to provide their services for the even lower rates budgetholders may be able or willing to pay. Some agencies have used personal budgetholders as a wedge to expand into geographic areas where other providers have monopolies. Most respondents believed the personal budget option has made formal agencies more responsive to clients in at least some ways, although changes were often characterized as relatively minor.

England

In England, Direct Payment users can choose agencies or hire individual workers. While relatives may be hired as providers, there are very broad restrictions on consumers hiring relatives. Regulations stipulate that a married or unmarried partner of the disabled person who lives in the same household as the beneficiary cannot be employed by the consumer, and no exceptions to this rule are permitted. Close relatives, defined as parents, parents-in-law, aunts, uncles, grandparents, sons, daughters, sons-in-law, daughters-in-law, stepsons or -daughters, siblings, or the partner of any of these people, are also excluded from being paid caregivers.

These restrictions are generally not controversial. When the national government implemented Direct Payments, it wanted to avoid substituting for the unpaid, informal support network. There is also concern that it would be hard to enforce an employment contract between relatives, particularly if families see the Direct Payments as a source of family income. Younger disabled people also resisted the idea of having to rely on family; they would rather set up their own independent households and have workers who are accountable to them as employees.

Available research indicates that inability to hire relatives may be an obstacle to participation by older people and minority groups. Focus group research and interviews with older persons indicate they would like to hire family members, in part because they fear strangers entering their homes or because they want to help support the efforts of their unpaid carers.³²

Among minority communities, there has been some attempt to bend the rules because of the need to find providers who can provide culturally appropriate services.

Germany

While some observers in Germany characterize the cash payment as a mechanism for consumers to buy care in the marketplace, most stakeholders portray the benefit as a way to support informal caregivers, especially daughters and daughters-in-law. In 1998, only 11 percent of beneficiaries who elected the full cash benefit purchased any professional services.³³ To most analysts, the cash payment's goal is to prevent erosion of informal care in the future as families become smaller and more dispersed geographically. For working-age women, this is in line with other aspects of German social policy (for example, child care) aimed at enabling women to withdraw from the workforce to care for their family, rather than at building up services that would enable them to combine work with family duties.

Despite introduction of the social insurance program, the proportion of caregivers who feel burdened remains at 80 percent, although the proportion that feels "strongly burdened" has declined somewhat, from 48 percent to 40 percent between 1991 and 1998.³⁴ The caregiving burden is felt most strongly by those who provide care to persons with dementia, regardless of their physical disability. There is also a strong correlation between feeling burdened and giving up a job to provide care.

The program has not led to major restructuring of households—for example, more parents moving in with their children. Twenty-two percent of persons receiving care at home live alone, and this proportion has remained virtually unchanged since before the program began.³⁵ However, slightly fewer people with long-term care needs report having no informal caregiver available since the program began (4 percent in 1998, compared to 9 percent in 1991). Furthermore, a larger proportion of individuals report having more than one person providing their care informally (70 percent in 1998, compared to 63 percent in 1991).³⁶ In a local survey, family caregivers were asked who coordinates care when multiple persons are involved.³⁷ From their responses, it appears that beneficiaries play only a marginal role in determining who provides their care in such cases. Typically, the primary caregiver, not the beneficiary, determines when each caregiver will work.

The extent to which family members are compensated for caregiving is difficult to determine for several reasons. To begin with, rather than caregivers being "hired" and "paid," often the funds simply are incorporated into the overall joint household budget. In addition, funds may be transmitted to the beneficiary's representative, who may also be the caregiving family member. Finally, payments to family caregivers may be made in kind, rather than in cash. Nonetheless, a small local survey of family caregivers found that half received cash payment, typically a fixed monthly amount; in two-thirds of those cases, the amount was equal to the full benefit amount.³⁸

Providing long-term care is considered something that family members do out of moral duty, not primarily to realize additional income. Consequently, any cash that family members

might receive for providing care is not taxed as income and is not counted toward eligibility for other programs, such as unemployment benefits.

Consumers can formalize their caregiving arrangements with informal caregivers by having the caregiver work as an independent employee or by establishing a “stand-alone agency.” Respondents believed these stand-alone agency arrangements were rare, perhaps only existing in rural areas that lacked other providers.

Labor Force Issues

In all three countries, labor force issues include shortages of workers and making sure that workers obtain the wages and fringe benefits to which they are legally entitled. Traditional labor relationships are complicated by the major role informal caregivers play in consumer-directed home care. Ironically, given Germany’s reputation for strict and expensive regulation of labor conditions, informal caregivers do not have the formal protections that workers do in the other countries because cash beneficiaries rarely “hire” them as workers.

The Netherlands

In the Netherlands, home care workers are usually less-educated, younger women with children, who work part time. Compared to many other countries in Europe, the Netherlands has a relatively low female labor force participation rate. Immigrants are not a major part of the long-term care workforce, although immigrants from Suriname (a former Dutch colony) play a noticeable role. Reportedly, other significant immigrant groups—primarily Moroccans and Turks—frown on having women work in other people’s homes.

There is a general shortage of long-term care workers, especially for agency home care workers and in large cities, such as Amsterdam. The lack of workers is now a major constraint on the growth of long-term care services, including personal budgets. Since home care agencies cannot deliver more services, this factor has muted some of home care agencies’ skepticism about personal budgets. Some government officials, especially in the labor ministry, worry that personal budgets will exacerbate the shortage of workers in formal agencies, and that workers will end up in work situations that do not provide wages and fringe benefits as good as the ones agencies provide. However, an early study of the program found that only 4 percent of care providers resigned from their jobs with home help organizations to work for budgetholders.³⁹

Independent providers in the Netherlands are legally entitled to a number of fringe benefits far beyond what is typical in the United States, including health insurance, sick leave, disability insurance, and vacation. As an employer, budgetholders also have the duty to make sure their employees can do their work safely, and employers must have liability insurance, which is offered by the SVB. While these requirements provide substantial protections for workers, they also result in quite high payment rates. Compared to workers who are employed by agencies, however, independent providers receive fewer fringe benefits.

England

Most stakeholders agreed there was a general shortage of workers available in the long-term care market, which has led to some Direct Payments users having difficulty in recruiting personal assistants.⁴⁰ The problems seem particularly acute in the southern part of England, where unemployment is quite low and housing costs are high, so few low-wage workers are available locally.

Some observers reported that one of the advantages of working for Direct Payment users is that workers may have more flexibility to negotiate schedule and tasks. On the other hand, some stakeholders argued that being an individual worker under Direct Payments has disadvantages compared to being employed by a local social service authority with union protection. The disadvantages include isolation and lack of the peer support available in agencies, lack of union protection against arbitrary decisions by users, lower benefits in some cases, and lack of access to private pensions. The limited available data do not suggest much wage differential between independent workers and employees of local social service authorities, however. Comparisons with workers in private agencies appear to be harder to make because private agencies are usually not unionized and generally have lower costs.

Germany

In Germany, since the cash benefit is used mostly to support informal caregivers, there are fewer formal labor issues and more attention is focused on how the program supports informal care. To further the family caregiving goal (regardless of whether the beneficiary chooses the cash or service benefit), the program covers respite care for informal caregivers (up to four weeks), and pension credit is awarded to persons providing substantial levels of unpaid services who are not otherwise gainfully employed for more than 30 hours per week. In 1999, approximately 574,000 people, 90 percent of whom are women, received pension credit as informal caregivers.⁴¹

Among formal providers, there is a shortage of long-term care workers. Surveys of workers in home care find that pressure to perform tasks quickly and the physical demands of the job (for example, lifting and bending) were primary areas of worker concerns.⁴² In one survey, a third of workers surveyed felt “empty” or “burned out” as a result of being around dying persons. Other areas of pressure or concern were working with persons with dementia, monotony, and the lack of intellectually challenging work.

Cost Containment

All three countries are currently experiencing economic difficulties that are reducing tax revenues and increasing public expenditures. Although each of these countries devotes a lower percentage of its gross domestic product to health and long-term care than does the United States, public programs play a larger role in financing care in these countries than they do in the United States. Each country is concerned about controlling expenditures in long-term care and in consumer-directed home care. This is particularly a concern in Germany and the Netherlands, where long-term care is provided through an insurance mechanism. In England, budget

appropriations levels can control aggregate expenditures but at the cost of narrowing eligibility for services or establishing waiting lists. In all three countries, policy interest in consumer-directed home care is driven at least partly by the notion that it is a less costly way to provide care, at least on an individual basis. Concern about increased demand, however, raises doubt about whether it saves money overall.

The Netherlands

In the Netherlands, until recently, aggregate AWBZ expenditures were controlled through a global budget. As part of that system, expenditures for personal budgets were limited. The conversion to an open-ended entitlement program has resulted in rapidly increasing expenditures for personal budgets, since this is the one component of the system that is not fully limited by supply constraints. Reimbursement rates for agencies, on which the budgets are calculated, have received rate increases to cover inflation. The primary mechanism for controlling the costs of personal budgets is the 25 percent discount applied when calculating the amount consumers receive relative to agency prices. This discount is based on the theory that independent providers do not incur the overhead costs of agency providers. In addition, while the cost-containment effect would be only indirect (since budgets are calculated based on payment rates for agency providers), independent providers are thought to receive lower wages and fewer fringe benefits than agency workers.

England

In England, localities' budgets have been under pressure since the 1980s.⁴³ In response, localities have contained costs by tightening eligibility standards, imposing service charges, and narrowing the range of services they provide. For example, some localities will not provide services to people who only need homemaker services. Localities also had set up waiting lists for assessments and services as a method of containing costs. In addition, Direct Payment amounts are not supposed to exceed the cost of services (care and administrative) to the locality of providing services directly. However, localities can increase the payment if they believe that would be cost effective. Available evidence does not suggest large wage differences between independent providers and local social service authority workers.

Germany

Germany began its long-term care insurance program with the belief that the overall supply and use of services was inadequate. Thus, one of the goals of the program was to expand long-term care services overall, and home care, in particular. A related goal was to spend less on means-tested social assistance for long-term care, shifting funding to the social insurance program. The program has met all of these goals. For example, about half of program expenditures are for noninstitutional settings, one of the highest percentages among the developed world.

Until recently, program expenditures were below initial projections, allowing for substantial buildup of financial reserves. The lower expenditures were due mostly to a higher than expected number of home care beneficiaries choosing the lower-cost cash option rather than

services. By 2002, however, expenditures slightly exceeded income and the program was forced to rely a bit on reserves. Most of the system's cost-containment mechanisms focus on preventing long-term care insurance funds from increasing revenue or spending more than is raised by premiums, without supplying many levers to actually control costs. The structure is designed to force policy makers to explicitly decide either to raise more revenue or to cut spending.

For the program as a whole, including the cash benefit, the primary cost-containment mechanism has been not to increase benefit levels for inflation. Indeed, neither the maximum spending levels on the service side or the cash benefit levels has increased at all since the program's inception (1995 for home care and 1996 for institutional care). As a result, real benefits have eroded substantially, although reimbursement rates for services have increased somewhat. It is surprising that agency and institutional providers are only gradually showing displeasure at the growth in payment rates, and home care providers less than institutional providers. Since there are no regional adjustments of benefits, a more pressing political issue is the geographic variation in reimbursement rates, which is greater than the erosion in benefits due to inflation.⁴⁴

Quality Assurance

The quality of consumer-directed services is of serious concern to policy makers in the United States. Traditional agency-directed home and community services programs attempt to ensure quality by relying heavily on government regulations that require professionals to provide services, require training for paraprofessional staff, and require agency supervision of paraprofessionals. While home care is generally less regulated than institutional care, almost all of the formal quality assurance mechanisms for agencies are lacking in consumer-directed care in The Netherlands, England, and Germany. In all three countries, individual consumers are generally responsible for quality assurance under consumer-directed care. Quality of care for consumer-directed home care is not perceived in any of these countries as a major issue, although none of the countries systematically collects the information necessary to determine whether there is a problem. The heavy use of relatives as caregivers in Germany and the Netherlands complicates any effort to regulate this type of care and, arguably, may make it less necessary.

The Netherlands

In the Netherlands, beneficiaries have a duty to purchase care of "adequate quality," but outside intervention occurs only if there is a clear indication of major problems. There are no training requirements for persons providing care to budgetholders, except for those providing skilled care, in which case personnel must have the appropriate license.

England

Similarly, it is up to users to ensure the quality of the services they receive under the Direct Payments option in England. In some localities, case managers assess users' situations six weeks after services begin, then at six months, and then once a year to ensure they are receiving

the services they need. There are no training requirements, although there is some debate about whether individual workers should meet the new standards that agency personnel must meet.

Germany

For persons receiving cash payments, the initial medical office assessment and “control” visits by home care agencies every four to six months are the primary mechanism to ensure that adequate care is being provided to the beneficiary. However, it is extremely rare for persons to be denied the cash option initially or for it to be terminated. As part of new quality initiatives, the content of control visits and provider responsibilities is being examined more closely and standardized. Providers conducting control visits are now supposed to document what care is available and what additional care is suggested if there is excessive burden on caregivers. The sickness fund is then responsible for reviewing suggestions and following up where it appears to be necessary.

Since more German home care beneficiaries at the most severe level of disability (which requires at least five hours of care per day, including nighttime) live in the community rather than in a nursing home, some observers are concerned about family burnout and the quality of informal care. These experts also see a need for more attention to psychosocial issues within the family or caregiving group, rather than a narrow focus on the physical needs of the beneficiary. The sickness funds run educational classes on home care for informal caregivers, although these are not mandatory or very extensively used.⁴⁵

Conclusions

As the United States explores ways of expanding home and community services for older and younger people with disabilities, policy makers increasingly are considering the potential role of consumer direction. Although consumer-directed services are moderately well established for younger people with disabilities in this country, they are less common among programs for older people. This study assessed the experience of the Netherlands, England, and Germany in running national programs of consumer-directed home care to identify issues for U.S. policy makers.

There are several key policy observations. First, consumer-directed home care is growing in importance in the three study countries, as it is in the United States. While it accounts for only about 2 percent of home care beneficiaries in England, consumer-directed home care now accounts for about 10 percent of home care beneficiaries in the Netherlands (and is growing rapidly) and 72 percent of home care beneficiaries in Germany (87 percent if combination cash and service beneficiaries are counted).

Variations across the three countries seem to depend less on the inherent characteristics of consumer-directed care and more on labor market conditions and how governments have chosen to structure the program. In the Netherlands, the bureaucratic administrative system has been a barrier to expansion. The rapidly increasing numbers of persons using consumer-directed home care is in response to supply constraints on nursing home beds and home care agencies’ inability to hire enough workers to increase the volume of services. Participation in England

seems to be limited by the local authorities' attitudes toward the older population and people with disabilities. It remains to be seen whether the national government's desire to promote this option will succeed. By contrast, Germany's willingness to offer the cash option broadly and to monitor only minimally seems to have resulted in extremely broad participation, and, at least thus far, there has been little or no scandal or political backlash.

Contrary to the expectations of some observers, consumer-directed home care in the three countries is used by older as well as younger persons with disabilities and by people with severe as well as mild disabilities. This is less so, however, in England. The Netherlands and Germany routinely allow cognitively impaired persons to participate in these programs, relying on surrogates to make decisions for the consumers. Although this is a reasonable accommodation to the limits of the cognitively impaired, it must be recognized that surrogates' decisions are likely not perfect representations of the choices clients would have made if they were not impaired. At least some of the decisions surrogates make will reflect their own preferences, schedules, and interests rather than those of the client. Moreover, the care situation becomes even more complicated when surrogate decision makers are also paid providers. The potential conflicts of interest are one reason why England does not permit close relatives to be paid caregivers.

Second, the administrative complexity of consumer-directed home care in the three countries varies as a function of three dimensions: how comfortable policy makers are in giving administrative responsibilities to consumers, how protective government officials are of people who work for consumer-directed beneficiaries, and how determined program administrators are to ensure that funds are spent solely on approved services. At one extreme, the Netherlands has a very complicated system that has been a major source of frustration to beneficiaries. In England and especially the Netherlands, the system is more complicated because there are more checks to ensure that the money is spent on approved long-term care services. The Dutch are simplifying their administrative system, but at the cost of increasing the burden on consumers and workers. In Germany, administration is very simple because consumers are left almost completely on their own to decide what to do with their funds; but that also means that they receive little help in putting together a package of services.

Third, given the concern by some observers about the capability of people with disabilities to handle management tasks, it is somewhat surprising that the three countries provide only modest help with the administrative tasks inherent in consumer direction, leaving clients mostly to find their own way. The Netherlands and England provide the most help with handling social insurance and other taxes and paying the worker; since few people are formally "hired" in the German system, very little formal assistance is provided, although it has been increasing slightly.

Fourth, reflecting the more developed social protections in European countries, consumer-directed home care workers have higher wages and far better fringe benefits than similar workers do in the United States. For example, workers in the Netherlands have health insurance, sickness and vacation leave, and pension coverage, and employers must have liability insurance. These fringe benefits are virtually unheard of in U.S. government-sponsored consumer-directed home care programs. While these fringe benefits do improve workers' quality of life, they add significantly to the cost of services. Despite these advantages over long-

term care workers in the United States, there is still a shortage of long-term care workers in all three countries. Especially in the Netherlands, the growth in consumer-directed home care (and the use of family caregivers) is, in part, a frustrated response to waiting lists for agency-provided care. This overall shortage of long-term care workers partly reflects that all workers, not just those in long-term care, are entitled to these fringe benefits. As a result, recruiting workers for a job that is physically and emotionally demanding remains difficult. There is some evidence that consumer-directed home care can increase the paid long-term care workforce, although many of these workers were providing informal care before being hired as paid workers.

Fifth, while much of the policy interest in consumer-directed home care derives from a desire to empower people with disabilities and give them more control over their lives, this approach is also attractive to governments because of its lower per person costs. Payment rates for consumer-directed care are much lower than for agency care, partly because there is little or no payment for administrative overhead, which can be substantial for agencies. Moreover, while independent workers in these countries are compensated far better than their American counterparts, they tend to do less well financially than agency workers. Consumer-directed workers often receive slightly lower wages (although perhaps not in England) and fewer fringe benefits than agency workers.

While costs per individual basis may be lower, these may be offset by an increased use of benefits by persons who would not use agency services or who could not use them because of supply constraints. Germany, however, which offers a highly desirable cash benefit, has not experienced an uncontrolled increase in use. Indeed, enrollment is close to what had been anticipated initially.

Sixth, probably the most contentious issue in the United States surrounding consumer-directed programs relates to whether the quality of care is adequate and how services should be monitored. Compared with agency-directed care, consumer-directed services lack the standard quality assurance structure of paraprofessional training, supervision by professionals, and provision of technical services by professionals. Despite some concern about service quality, the three countries have taken minimalist approaches to monitoring quality. Although most services provided in consumer-directed programs are unskilled, the lack of training requirements and monitoring is particularly striking at a time when proposals for increasing regulation of formal providers are commonplace. Nursing homes and home care agencies argue for a “level playing field” in regulation between them and consumer-directed home care. Consumer advocates and policy makers appear to have placed greater priority on maintaining flexibility and consumer choice in home and community services settings, fearing that increased regulation will replicate an “oppressive” nursing home setting.

In place of formal quality assurance mechanisms, consumer-directed programs rely on clients’ ability to fire unsatisfactory workers and hire replacements to ensure quality—in other words, the market. The current labor shortage, which makes recruitment difficult for all long-term care services, may threaten the quality of these services by undermining clients’ willingness to fire poor-quality workers, perhaps increasing the need for more formal quality assurance mechanisms. In addition, at least in Germany and the Netherlands, public officials are relying on the belief that relatives are much more likely than strangers to provide high-quality care.

Finally, a major labor force-related issue is that a very significant portion of independent workers are family members. Many of the policy issues discussed above—management, training, quality assurance, and payment levels—take on a very different cast if the independent provider is a family member or friend rather than a stranger. The adage, “blood is thicker than water,” may account for some of the countries’ relatively laissez-faire attitudes toward consumer-directed home care. To a significant extent, especially in Germany, these programs can be viewed as supports for informal caregivers rather than a service program that relies on the market.

The use of informal caregivers also illustrates the trade-offs between equity and efficiency. For example, Germany’s cash payments can be justified on an equity basis in that they make family caregivers better off. On moral grounds, policy makers want to reward informal caregivers for their sacrifices. But from an efficiency perspective, the long-term care insurance program is spending a great deal of money without a resulting major change in behavior. Extensive informal care is being provided now in Germany, just as it was before the cash benefit was introduced. For people receiving the cash benefit, it is not clear that much has changed, although some observers think it is too early to tell whether the program will help to sustain provision of informal care.

In sum, the concept of consumer-directed home care challenges the protective nature of most home and community services programs for older people by asserting that clients want to and are capable of managing their own care. The experiences of the Netherlands, England and Germany suggest that these countries are moving ahead successfully in changing the nature of noninstitutional services in a way that gives people with disabilities more control over the services that are so important in their lives.

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PERSONAL BUDGETS IN THE NETHERLANDS

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Background

As is the case in other European countries, the Netherlands is an aging society. In 2000, 13.6 percent of the population in the Netherlands was age 65 and over, and 3.2 percent was age 80 and over.¹ The proportion of the population that is elderly is projected to nearly double, to 25 percent, by 2040.² Population aging will place additional burdens on government programs and society as a whole, but to some extent the Netherlands is better placed than many other European countries to meet these pressures because it has a large, funded occupational pension system in place,³ with employers meeting a significant portion of the cost.

Overall, health care, including long-term care, accounted for about 8.7 percent of the country's gross domestic product in 1998, a percentage that remained fairly stable during the 1990s.⁴ Insurance in the Netherlands is divided into "cure" and "care"—health/medical care and long-term care—although there is debate about combining them into a single system. Both are provided without a means test, but premiums and copayments are income-related. A major goal of proposed changes in both the acute and long-term care sectors is to introduce more competition and to make the system more demand-driven: in other words, to change from a "supply-led system to a demand-led system."⁵

Acute care insurance is provided by sickness funds, which cover low- and moderate-income persons, and private insurance, which covers upper-income individuals.⁶ Insurance provided by sickness funds is supervised by the Health Care Insurance Board (*College voor zorgverzekeringen*, CVZ).⁷ Under the Health Insurance Act of 1964 (Zfw), income-related premiums paid jointly by employers and employees primarily finance the sickness funds. In 2002, employers paid 6.25 percent of payroll and employees paid 1.70 percent of salary, up to an income ceiling of 28,188 Euros, to national health insurance funds.⁸ Higher-income persons may not participate in the statutory system, but virtually all such persons purchase private health insurance. There is no legal mandate to do so, however. Although health care is financed by insurance, the health care system is budgeted and highly regulated, with significant waiting lists for services. Medical care is provided predominantly by private providers and nonprofit organizations, largely organized along religious lines.

The Exceptional Medical Expenses Act of 1967 (*Algemene Wet Bijzondere Ziektekosten*, AWBZ) established the long-term care insurance program, which covers the entire population, including the upper-income population. The AWBZ covers a wide range of institutional, residential, and home care services and provides coverage to persons with physical and cognitive disabilities (such as Alzheimer's disease), developmental disabilities/mental retardation, and mental illnesses. Consumers have free choice of providers, although there are often local monopolies among service providers. A major effort is underway in the Ministry of Health, Welfare and Sport to "modernize" the AWBZ by making the system more consumer-oriented and "demand-led."

For home care, individuals choose between receiving services from an agency or consumer-directed home care, called “personal budgets” (*persoonsgebondenbudget*). Under personal budgets, individuals are allocated an amount of money for care they can use to buy services from independent providers or agencies. Although they are growing rapidly, personal budget expenditures are a small part of home care and a very small part of total long-term care expenditures. Until recently, personal budgets were deliberately limited to about 3 percent to 5 percent of expenditures for home care as a cost-containment mechanism. However, those restrictions have ended and, as of September 2002, personal budgets were about 10 percent of home care expenditures.

The AWBZ is financed primarily by a 10.25 percent payroll tax on the lowest income tax bracket, up to about 15,331 Euros after tax deductions, with no employer contribution. There is financial pressure to raise the contribution rate and political pressure not to. In general, however, there appears to be no significant political opposition to the level of contributions to finance the AWBZ, even though it is high by American standards.

Despite being an “insurance” program, the AWBZ traditionally has budgeted its expenditures rather than providing an open-ended entitlement. Due to funding constraints, there have been substantial waiting lists for services, and so-called bed blockers, hospital patients eligible for discharge to a nursing home or home care who are still in the hospital because services are not available, account for 4 percent to 5 percent of hospital patients. In 2000, 54,300 persons were on the waiting list for home care services, and waits for services averaged eight weeks (with a range of three to 31 weeks, depending on the type of service).⁹ Moreover, to cope with the shortage of funding and workers, agencies reportedly sometimes provide clients with fewer hours of services than their care plan authorizes.

A recent court decision, however, ruled that waiting lists and budgeting are inconsistent with insurance principles and ordered the AWBZ to operate as an open-ended individual entitlement. The AWBZ has functioned in this new way since 2001. Except for personal budgets, however, supply constraints, including labor shortages, have kept the waiting lists quite long. The government’s general position is that waiting lists should be eliminated. Personal budgets have functioned as an escape valve for people frustrated with the waiting lists for services from agencies, with many people opting for personal budgets as a way of taking control of the situation and getting some services more quickly.

In addition to the AWBZ, a number of other government programs cover long-term care services; the most important of these provides medical aids, home adaptations, and durable medical equipment (Services for People with Disabilities Act, *Wet Voorzieningen Gehandicapten*, WVG). Moreover, the disability insurance program has many beneficiaries, and has made efforts to tighten eligibility rules and encourage employment; these initiatives have not been very successful.

Home Care Benefit: Agency services and Personal Budgets

The AWBZ covers home care through in-kind home care services provided by agencies and through “personal budgets.” Beneficiaries can choose between the two options. Pressure for

consumer-directed home care initially came from organizations representing younger people with disabilities who wanted more consumer control. In their view, the home care agency “was in charge of your life and your home”; agencies, not clients, decided who would come, when they would come, and what services they would provide. Disability groups contended that it would be better if clients controlled the funds that normally would have gone to agencies. While there was generally broad support for increased consumer influence, insurers and home care agencies initially opposed the new strategy because of concerns about consumers’ ability to handle the tasks required and the quality of care. To test the concept, demonstration projects, which were generally viewed as successful took place from 1991 to 1993.¹⁰

Personal budgets for nursing and home care (primarily for older people and younger persons with physical disabilities) were implemented in 1995 as a regular, although budget-limited, component of the AWBZ home care benefit. In 1996, a similar program was established for persons with developmental disabilities/mental retardation, and in 2001, a program was established for persons with mental illnesses. In addition, a personal budget system for intensive home care was established in 2000, designed primarily as an end-of-life benefit. Finally, in 2001, a demonstration project was initiated to examine a personal budget system for persons with severe physical disabilities needing highly intensive levels of personal care. This demonstration has been rendered moot by the elimination of the restriction on the number of hours of personal care that clients could receive.

To simplify administration, all of these separate programs are to be merged into a single system as part of the reform that began to be phased in starting in April 2003. In the new system, people with the same functional needs are treated equally, regardless of the source of their disability. Some respondents were concerned about the potential impact on higher-cost persons with developmental disabilities and the loss of administrative staff expertise about particular disabilities.

The introduction of personal budgets had several goals that are consistent with the notion of making the system more “demand-” rather than “supply-driven.” The main goal was to empower consumers by giving clients more control over their care.¹¹ Under the personal budget system, clients, not agencies, make major decisions about how their care is to be delivered.¹² Another goal was to increase competition among providers to make them more responsive to consumer needs. In many geographic areas, individual home care agencies have a monopoly. It was also hoped that personal budgets would stimulate the entry of additional agencies, providing more competition among home care providers. A final goal was to help control the overall rate of increase in expenditures. Because of the way personal budgets are constructed, they cost less than agency-provided services on an individual, if not an aggregate, basis.

Initially, expenditures for personal budgets were very limited, which effectively capped the number of participants. Total personal budget expenditures were approximately 200 million Euros in 2001, of which 130.5 million Euros was for nursing and personal care, 61.3 million Euros was for persons with developmental disabilities, and 8.7–10.5 million Euros was for persons with mental illnesses. For nursing and personal care services, total home care expenditures were 1.79 billion Euros, so personal budgets were about 7 percent of total home care expenditures.¹³

In response to the court case discussed above, the budget limitation was removed and the number of budgetholders has increased very rapidly, although from a small base. As of September 2002, about 44,000 beneficiaries had chosen personal budgets—75 percent in nursing and personal care program, about 20 percent in the developmental disabilities program, and about 5 percent in the mental illness category. The program specifically for persons with physical disabilities is extremely small, accounting for much less than 1 percent of personal budgetholders. The September 2002 number of personal budgetholders is more than six times the number of people with personal budgets in 1998.¹⁴ The general assumption among policy makers is that personal budgets will grow to about 20 percent of total home care beneficiaries, then level off.

As with other AWBZ services, personal budgets are available without a means test. Unlike Medicaid home and community-based services waivers in the United States, which are limited to persons who need institutional-level care, persons with fairly low levels of disability are eligible to receive services. Historically, only long-term disabilities were covered as well.

The monetary amount of the personal budget for home and nursing services is determined by multiplying the number of hours needed of each of eight services times the national average payment rates for those services, then reducing that amount by 25 percent and an income-related copayment.¹⁵ The 25 percent discount is supposed to account for the fact that independent providers do not have the overhead costs that agencies must incur. While people receiving services from agencies are billed by providers for and actually pay the copayment, personal budgetholders almost universally treat the copayment as a further discount in their budget allocation and do not pay an additional amount when they purchase services. The other personal budget programs have similar, but somewhat different, methods of calculating the budget.¹⁶ Once merged into a single program, the budget calculation methodology will most closely resemble the approach used for the home and nursing budget.

In addition to the overall budget, individuals directly receive up to 1,091 Euros annually, which is meant to fill gaps in services and for small personal items. There are no restrictions on how these supplementary funds may be used, and beneficiaries do not have to account for how the money is spent.

Budgetholders are legally required to spend their budget only on AWBZ-covered services, and this requirement is monitored quite closely. For example, tickets to a movie are not covered, but help to get to a movie could be covered. What is and is not covered is sometimes an issue and subject to revision. Services are not limited to what is provided in the home. In general, there is not much controversy over covered services for the older population, but there is for persons with developmental disabilities.¹⁷

There are several issues regarding the benefit. First, there are reportedly substantial differences in the size of the budgets across geographic areas, which various stakeholders see as unfair. Some observers also contend that assessment agencies take the supply of services into account when determining what people need, reducing the amount of care in geographic areas where there are waiting lists. Second, as with Medicaid home and community-based services waivers, there are limits on the size of the budget an individual may receive. Although, most

clients receive far less, personal budgets for home and nursing care have a ceiling of 300 Euros per day, which roughly represents the upper limit of the cost of nursing home care. Disability advocacy groups oppose these ceilings as arbitrary. Third, there are complaints that, after taking the discount for agency overhead (and the income-related copayment), the budget level is too low, making it difficult to obtain needed services, especially from agencies. Government officials, however, note that people are conservative in their service use and save their budgets for potential emergencies. As a result, they spend only about 85 percent of what they are allocated. Consumer advocacy groups concede that it is possible to obtain discounted rates for less-skilled care, but for more complex services, they contend, consumers have to pay full charges.

Administration

Administration of the long-term care system is complex and has been a major policy issue in the Netherlands, especially as it relates to personal budgets. There are numerous controls in the system to ensure the money is spent only on allowable services and workers receive adequate compensation and protections. In interviews, the system was almost universally characterized as bureaucratic and cumbersome, with too many layers and too many decision makers. Several reorganizations in the administration of personal budgets have added to the instability. A major new administrative system was implemented, starting in April 2003. The basic administrative elements of personal budgets include needs assessment, setting payment rates, budget approval, and paying for services.

Assessments

Starting in 1998, a single point-of-entry system was created for clients seeking home care and services in residential and nursing homes in the Netherlands. Assessments of individuals' needs are done by about 80 independent Regional Needs Assessment Boards (*Regionale Indicatie Organen*, RIOs), which are administered by the municipalities. It is the RIOs' responsibility to assess the long-term care needs of individual clients objectively and to determine the kinds and amount of care needed, irrespective of financial constraints. The RIOs' assessment of the amount of each type of care needed is important information for the health care offices, but these estimates are not binding; the budgets are actually authorized by the regional health care offices. Before creation of the RIOs, the assessments were done by home care agencies, but some argued that this resulted in conflicts of interest and assessment inconsistencies. Despite the new system of RIOs, concern remains about the objectivity of the system.¹⁸ Some observers also argued that a more "objective, expert-only" assessment would result in less-expensive care plans. Because of backlogs, it can take several months to receive an assessment. Clients are reassessed annually and may also apply for a reassessment when they believe they need more care.

The assessments have traditionally been very broadly service-oriented. In 2001, 83 percent of persons receiving the nursing and personal care budget were assessed as needing domestic help, 34 percent were assessed as needing personal care, and 20 percent were assessed as needing home nursing.¹⁹ Beneficiaries are estimated to need an average of 3.8 hours of

personal care per week, which is not very high by American standards, in part because many beneficiaries have low levels of disability.

The new system changes the long-term care assessment categories by switching to assessment of seven major functions—home care (housekeeping and grocery shopping); personal care (relating to the activities of daily living, involving touching the body); supportive care (supervision and cueing with little expectation that a person eventually would be able to perform the activity without help, for example, helping a severely cognitively impaired person ride a bus); activating care (like supportive care, but with the expectation the client eventually will not need any more help; this has more of a teaching component than supportive care), treatments (very specific medical treatments), and accommodation (room and board when a person needs round-the-clock care). Funding for treatments and accommodation, the last functions, are not included in personal budgets—costs vary too much depending on the treatment, and accommodation is not covered for home care clients. By unbundling services along specific functional needs, the government hopes consumers will mix and match services across a number of providers in ways that work best for them. The government’s goal is to give consumers new possibilities for organizing care.

A major change, this new assessment system raises several issues. Since the new functional categories are not the usual way in which services are provided, there is the question of how assessors can translate these functional assessments into number of hours or other units needed and how accurately costs can be calculated for them. To address this problem and to help ensure consistency, the government plans to provide assessor training. In addition, some consumer advocates for specific groups, such as people with developmental disabilities, are concerned that the move to a more generic assessment system will result in the loss of specialized understanding of the needs of particular groups. They are also concerned that the new assessments’ complexity will increase variation in the assessed needs for persons with identical needs.

In determining the amount of services needed, availability of informal care is taken into account, which is controversial, especially among advocacy groups for younger people with disabilities, who think dependence on informal care is undesirable. Advocacy groups representing older people also think it is unfair because it violates insurance principles and places an undue burden on family members. Assessors contend, however, that disregarding availability of informal care would be too expensive because they would have to increase the amount of care for people who do not need it.

Payment Rates

Payment rates for home care providers and, indirectly, the level of personal budgets, are set by the National Health Tariffs Authority (*College Tarieven Gezondheidszorg*, CTG), which calculates reimbursement rates for services that account for about 85 percent to 90 percent of national health expenditures.²⁰ Labor agreements are a major source of the data the agency uses to set payment rates. Personal budgetholders are not bound by these payment rates for individual service providers and are free to decide what wage they will pay, provided it at least meets minimum wage requirements.

Approval of the Personal Budget

The 31 Regional Care Offices (*Zorgkantoor*) are the local administrative agents of the insurance companies; for the AWBZ, administrative functions for all of the insurance companies are performed by one regional office. Previously, each insurance company handled its own clients. These offices normally pay long-term care claims, although not for personal budgets, where their responsibility has been limited to authorizing the personal budget and its level. In some cases, there is a back and forth with the RIOs about the rationale for the types of services and the number of hours.

Paying Claims and Other Administrative Responsibilities

Initially, Per Saldo, a consumer advocacy member organization of budgetholders, was given the responsibility for paying providers under personal budgets, but the administrative requirements proved to be quite complex and there were many problems. For the last several years, the Social Insurance Bank (Sociale Verzekeringsbank, SVB), which is in charge of paying beneficiaries under several pension systems, has been responsible for most of the financial management of personal budgets: approving contracts with providers, making tax and social insurance payments, offering liability insurance to budgetholders, gathering data, and actually paying providers. It was thought that this organization, which had expertise in running large public programs, would be better placed than Per Saldo to administer the budgets' financial aspects.

For providers to be paid, they must have a signed contract with their budgetholders, which has to be reviewed and approved by the SVB in the pre-April 2003 system and by the regional health care offices under the post-April 2003 system. All contracts terminate on December 31, so if the SVB does not have an approved contract, payment can be delayed. Budgetholders must certify that work was performed for the worker to be paid by the SVB.

Although there is a perception that administration by the SVB is better than it was by Per Saldo, payments under the SVB have been late, and there have been other administrative difficulties. Starting April 2003, the money goes directly to the budgetholders and most administrative functions are transferred to the budgetholders. In the new system, budgetholders themselves will get periodic disbursements of their budgets based on the size of their budget. They will then be responsible for paying their workers and other providers.

This change in administrative structure simplifies the system in some ways, but also shifts much of the administrative burden to beneficiaries and workers. The level of burden on consumers (but not workers) is reduced by the fact that independent providers who work for an individual for two days a week or less are responsible for making their own social insurance and other tax payments. Thus, those tax payments are the worker's responsibility rather than the consumer's. It is estimated that 90 percent to 95 percent of budgetholders have employees who are in this category. The 5 percent to 10 percent of budgetholders who employ workers for three or more days a week can continue to use the SVB to handle administrative functions at no cost to them if they so choose. Others can choose to contract with another agency for this work. All

budgetholders are responsible for filing an annual wage statement, the equivalent of a W-2 in the United States.

In the new structure, budgetholders must submit all payment records to the regional offices for approval after the fact. Individuals who make improper payments for uncovered services or other items are subject to cost-recoupment efforts through reductions in prospective budget allocations, retrospective recovery of payments, or suspension from the personal budgets option.

Some observers worry that clients may find the new system to be too burdensome and drop out, especially consumers with psychiatric disorders. Several stakeholders did not think clients are capable of handling the administrative responsibilities. Under the former system, the SVB did a lot of “hand holding” with clients, which is not possible in the new system. In addition, the SVB fears that the uniformity (and equity) possible with a single office of the SVB administering all personal budgets will not be possible now that responsibility is decentralized to the 30 different health care offices. Also, with responsibilities so decentralized, skeptics of the reorganization argue that it will be harder to monitor activity and identify problems. Moreover, it took the SVB a long time to develop its administrative systems, and it will take the health care offices a long time as well.

Finally, under the former system, there was not too much concern about fraud and abuse because budgetholders directly controlled very little money, aside from the supplemental funds that went directly to the consumer. Now that the budgetholders have complete control of all the money, opponents worry that there is a greater risk of fraud and abuse. To address this problem, the Ministry of Health, Welfare and Sport and others are advising budgetholders to have the money deposited into a separate bank account to be used only for their long-term care expenses. With the money in a separate account, the possibility of commingling of personal funds should be reduced. For the system as a whole, some consumer groups are concerned about the increased power of the regional offices run by the insurance companies under the new arrangement.

Beneficiaries

Although consumers face administrative problems, the consensus is that personal budgetholders are happy with the personal budget system. Consumer advocates contend that personal budgets allow the client to be “the boss in his own home.” One knowledgeable respondent reported that most younger people tend to choose personal budgets, as do many persons with no previous experience with the system. People who have been in the in-kind system tend to stay with that system.

In terms of eligibility, there are no limitations on who can use the personal budget option, in terms of age or type or severity of disability. Officially, the regional health care offices can decide that a personal budget is inappropriate for a particular individual, but it is rare for applicants to be denied. In 2001, for the home care and nursing budget, the median age was 58 and three-quarters of the recipients were women.²¹ Many personal budgetholders have relatively

low levels of disability, needing only housekeeping services, so managing these services may not be overly complex.

When individuals have Alzheimer's disease, a stroke, or other cognitive impairments, their family and friends make most of the decisions about personal budgets. Among persons with developmental disabilities, personal budgetholders tend to be those with younger, relatively assertive parents.²² The use of surrogate decision makers raises a number of issues about the ability and willingness of proxies to reflect the desires of individual consumers.

A number of organizations help budgetholders negotiate the system on an individual basis, especially in hiring workers, but limited mechanisms are in place to systematically address issues such as recruitment, training of workers and consumers, management of workers, establishing backup systems in case of illness or other absences, among others. Per Saldo, the organization of budgetholders, informs, advises, and supports budgetholders and represents their interests in the political and policy process.²³ It is very active providing information and advice to budgetholders, organizing meetings, running a help line, and representing budgetholders in different settings. Like many other advocacy organizations in the Netherlands, it is supported largely with government funds. The elderly advocacy groups are trying to obtain funding to provide additional client support, but there are conflicts with other groups over how much money will be allocated and who will receive it.

Service Providers under Consumer-Directed Home Care

Budgetholders buy services from independent providers, including family and neighbors, or from a regular home care agency. About 70 percent of budgetholders pay informal caregivers or other independent providers; about 30 percent use agencies. Founded 80 to 90 years ago, traditional home care agencies are part of religious-organized charities and social organizations. When budgetholders buy services from formal agencies, consumer advocates argue, budgetholders have more control over when and who provides services than is normally the case for those who use only agency-directed services.

For home care agencies, providing services to budgetholders is a way of making additional money, but staffing shortages limit what they can do. For agencies, contracting with personal budgetholders entails a level of risk they do not have under the services in-kind system—under the new system, they have to worry about people who do not pay their bills and clients who terminate their contracts. Some agencies do not charge clients their full costs (including overhead), recognizing the reduced funds budgetholders receive. When agencies provide this discount, however, they must consider how many budgetholders they can afford to serve and still cover their costs. In general, formal home care agencies already believe their rates are inadequate, so they are reluctant to charge even lower rates.

Some agencies have used personal budgetholders as a wedge to expand into geographic areas where other providers have monopolies. With personal budgets, clients can break open the market by deciding with whom they want to do business. Typically, insurers and others steer clients to traditional providers, making market entry difficult. So far, personal budgets have resulted in a modest increase in the number of home care agencies, most of which are very small,

for-profit organizations. Most persons interviewed believed the personal budget option has made formal agencies more responsive to clients, although the changes were often relatively minor.

Aside from informal caregivers and friends, consumers find workers through advertisements, notices on church bulletin boards, and a website run by Per Saldo. In one early study of the program, approximately 50 percent of individual care providers employed by budgetholders did not have paid work before they began these jobs, suggesting that the program was expanding the long-term care labor force.²⁴

As in most other countries, informal caregivers play a major role in consumer-directed home care in the Netherlands. About half of all budgetholders pay informal caregivers.²⁵ While there is some concern about paying for services that are already provided for free, and that paying informal caregivers can trap women in low-wage jobs with no advancement possibilities, the concept of paying family members, including spouses and parents, is widely accepted. Reportedly, budgetholders are relieved at being able to pay something to their informal caregivers to help compensate for the time these family members devote to them. According to some respondents, hiring parents, spouses, and other close relatives complicates decision making because these persons are both employees and also typically have a lot to say about the services the client receives and who provides them.

Older people are more likely to choose informal caregivers as their providers than are younger people with disabilities. Younger persons with physical disabilities tend to hire friends or an individual worker not previously known to the client. Their first choice is not to hire relatives, but they sometimes must do so because of the shortage of workers. According to advocates for younger people with disabilities, hiring relatives may leave the client dependent on family and can interfere with true independence.

Labor Force Issues

Home care workers are typically less-educated, younger women with children, who work part time. Compared to many other countries in Europe, the Netherlands has a relatively low female labor force participation rate. Although changing, the traditional expectation has been that only the husband would work. Immigrants are not a major part of the long-term care workforce, although immigrants from Suriname (a former Dutch colony) play a noticeable role. Reportedly, cultures among other significant immigrant groups—primarily Moroccans and Turks—frown on having women work in other people's homes.

There is a general shortage of long-term care workers, especially for agency home care workers and in large cities, such as Amsterdam. The lack of workers is now a major constraint on the growth of long-term care services, including personal budgets. Since home care agencies cannot deliver more services, this factor has muted some of these agencies' skepticism about personal budgets. Some government officials, especially in the labor ministry, worry that personal budgets will exacerbate the shortage of workers in formal agencies, and that workers will end up in work situations that offer lower wages and fewer fringe benefits than agencies provide. However, one early study of implementation of personal budgets found that only 4

percent of care providers resigned from their jobs with home care organizations to work for budgetholders.²⁶

Independent providers are legally entitled to a number of fringe benefits far beyond what is typical in the United States. Workers are entitled to health insurance, sick leave, disability insurance, and vacation. As employers, budgetholders must make sure employees can do their work safely, and employers must have liability insurance, which is offered by the SVB. While these requirements provide substantial protections for workers, they also result in quite high payment rates, about 20 Euros an hour, only about half of which is actually wages. Independent providers tend to receive fewer fringe benefits than workers who are employed by agencies, however.

It is the responsibility of agencies and independent providers to arrange for backup care if the worker is sick or does not show up for some reason. In general, for personal budgetholders, it is “catch as catch can.” Only a small percentage of people have any formal arrangement to deal with unscheduled absences.

Quality Assurance

Quality of care in long-term care is not perceived to be a major problem, although nursing home care is not thought to be as good as it should be (the Dutch do believe, however, that care is better there than in most other countries).²⁷ While home care agencies must meet various regulatory requirements, these requirements do not apply to independent providers. For agency providers, there are lots of groups “looking at your fingers to see if they are clean,” as the Dutch say.

In contrast, personal budgetholders are de facto responsible for quality assurance, and they have a duty to purchase adequate-quality care. External intervention occurs only if there is a clear indication of major problems. There are no training requirements for persons providing care to budgetholders, except for those providing skilled care, in which case personnel must have appropriate licenses. Personal budgets do not provide money specifically for training.

Financing and Cost Containment

Since the Dutch economy is not growing rapidly, cost containment is an important issue, especially with the AWBZ now operating as an open-ended entitlement program. Some observers believe expenditure increases eventually will force the AWBZ to return to a budgeted program. So far, the AWBZ has not limited eligibility, for example, to people with more severe disabilities.

Government officials are attracted to personal budgets, in part, because of their greater potential to reduce expenditures compared to the cost of providing agency services, at least on an individual basis. As noted above, these cost savings are the result of the 25 percent discount applied when calculating the amount of money consumers receive relative to agency prices. In addition, the per diem cost of personal budgets cannot exceed that of nursing home care. Consumer groups and providers, however, are pushing to eliminate the discount for overhead

and have resisted the per diem limit. Advocates and providers argue that budgetholders have had to absorb many administrative costs, and that the discount prevents people from buying services from agencies, which do have these administrative expenditures. On the other hand, the attraction of managing one's own services and the fact that there are waiting lists for other services has resulted in an increase in use of and expenditures for this benefit.

Endnotes

¹ Organizational for Economic Co-operation and Development. *OECD Health Data 2002* (Paris, 2002).

² Sociaal Economische Raad. *Gezondheidszorg in het licht van de toekomstige vergrijzing (Health Care and Population Aging)* (The Hague: Sdu Uitgevers, 1999).

³ Carey, D. "Coping with Population Aging in The Netherlands" Economics Department Working Paper No. 325, ECO/WKP(2002)11 (Paris: OECD, 2002).

⁴ World Health Organization. *World Health Report (2001)* (Geneva, 2002).

⁵ Ministry of Health, Welfare and Sport (Ministerie van Volksgezondheid, Welzijn en Sport). *Nota Vraag aan bod. Hoofdpijnen van vernieuwing van het zorgstelsel (The Question of Demand. An Outline of Proposed Modifications to the Health Care system)*. Proceedings of the Lower House 2000–2001, 27 855, nos. 1–2 (The Hague, 2001).

⁶ Ministry of Health, Welfare and Sport (Ministerie van Volksgezondheid, Welzijn en Sport). *Health Insurance in The Netherlands, Status of 1 January 2002* (The Hague: Author, 2002). The statutory sickness funds are primarily for employees with salary below 30,700 Euros and self-employed persons with income below 19,650 Euros in 2002, which accounts for about two-thirds of the Dutch population.

⁷ Health Care Insurance Board (College voor Zorgverzekeringen). *Forerunner at the Heart of the Health Care System* (Amstelveen, n.d.).

⁸ Ibid.

⁹ de Boer, A., J. Helsing-Wagner, M. de Klerk, and S. Kooiker. "Take Up Services and Care Provisions." In M. M. Y. de Klerk (ed.), *Report on the Elderly 2001* (The Hague: Social and Cultural Planning Office of The Netherlands, 2001), pp. 167–211. Providers are required to accept the most urgent cases off the waiting list.

¹⁰ Miltenburg, T. et al. *A Personal Budget for Clients: Summary of an Experiment with Cash Benefits in Home Care in The Netherlands* (Nijmegen: Institute for Applied Social Sciences [ITS], 1996).

¹¹ Ramakers, C. C. “The Personal Budget System in The Netherlands.” Paper presented at the Conference on Social Care Markets, Milan, 2001 (Nijmegen: Institute for Applied Social Sciences [ITS], 2001).

¹² One observer argued that some of the popularity of personal budgets was based on the false notion that being master of your own fate means that you can get whatever you want, whenever you want it. Especially given the labor shortages, he did not think this was realistic.

¹³ Ramakers, 2001, op.cit.

¹⁴ Ibid.

¹⁵ The income-related copayment is based on two-year-old tax returns; assets are not taken into account. The copayment rates are slightly higher for persons age 65 and older than for persons younger than age 65, which is probably equalized by the lower tax rates for older persons. The maximum copayment is 124 Euros per week starting at approximately 39,000 Euros, but most people face fairly nominal copayments.

¹⁶ The budget for mental health care relates to the number of hours of counseling. For persons with mental handicaps, clients are assigned to one of eight categories based on their need for services and their age. Similar to the German social insurance system, each category has a specified budget.

¹⁷ Among persons with learning disabilities, five or six personal budgetholders sometimes pool resources to create a small residential setting, which is financially difficult because the budget is not geared to establish residential arrangements. It is also in contrast to the prevailing view that separate apartments is a better service arrangement, but they are not financially possible at the current personal budget level because of the overhead discount and the fact that personal budgets do not cover room and board costs.

¹⁸ Buijs, H.P.A.M., J. J. Busschbach, H. H. J. L. van Doorn, , B. van Dorp, E. C. M. Grootsholten, C. D. Prins, A.Y. Slijkuis, L. E. van Urk, and R. Voncken. “Gelijke Monniken Verschillende Kappen. Variatie in Indicaties voor thuiszorg (Variation in Home Care Allocation). *Medisch Contract* 55 (2000): 1395–97; Beemsterboer, W. G. M. “De Ratio de RIOs (The Reasoning of RIOs).” *TSG/Tijdschrift voor Gezondheidswetenschappen* 78 (2000): 238–43.

¹⁹ Ramakers, 2001, op. cit.

²⁰ College Tarieven Gezondheidszorg. *What is the National Health Tariffs Authority?* (Utrecht, 2000).

²¹ Ramakers, 2001, op. cit. For the budgetholders for persons with developmental disabilities/mental retardation, the average age was 25, and more than half are men; for budgetholders with mental illnesses, the average age is 41.

²² According to providers of services for persons with developmental disabilities, “while the influence of parents is generally positive, they don’t always represent the best interests of the child. They may not want what the child wants and is capable of. There is sometimes conflict with the professional judgment of the staff.”

²³ Per Saldo. *Take Control with Personal Budget (PGB)* (Utrecht, 2002).

²⁴ Baarveld, F., T. Miltenberg, and C. Ramakers. *Persoonsgebonden Budget Verpleging end Verzorging. Arbeidsmarktpositie van zorgverleners*. ITS, OSA-publicatie (Tilberg, OSA, 1998).

²⁵ Van den Berg, B., J. A. J. Van Exel, G. A. M. Van den Bos, M. A. Koopmanschap, and W. B. F. Brouwer. “Mantelzorg en Persoonsgebonden Budget (Informal Care and Personal Budgets).” iMTA rapport 02.59 (Rotterdam: Erasmus MC, iMTA, 2002).

²⁶ Baarveld, Miltenberg, and Ramakers, 1998, op. cit.

²⁷ For nursing homes, the principal policy issue is whether upper-income people should be able to supplement above the basic standard covered by the AWBZ.

DIRECT PAYMENTS IN ENGLAND

Jane Tilly, Dr.PH

Direct Payments programs in the United Kingdom (UK) allow participants to choose cash instead of home and community services from an agency or placement in a group residential setting; participants must use the cash to purchase services from an individual worker or a private home care agency. The UK's nations—Scotland, Northern Ireland, Wales, and England—all have somewhat different Direct Payments programs, which are part of larger long-term care systems that also differ from nation to nation. This discussion focuses on Direct Payments and its role in the larger home and community services system in England.

England's home and community services programs fall into three types: (1) those that are part of England's nationally administered National Health Service (NHS); (2) several cash allowances for persons with disabilities managed by the UK-wide Department of Work and Pensions; and (3) Community Care, which England's Department of Health oversees and localities' manage through their social services departments (SSDs). Direct Payments is part of the larger Community Care program.

The Direct Payments statute was enacted in 1996 after years of advocacy, primarily from the Independent Living Movement, largely composed of younger, disabled persons.* Advocates said people would improve their quality of life and gain more choice over their services under Direct Payments, and the program could reduce Community Care costs.

Initially, older persons could not participate in Direct Payments because of concern that there would be a surge in demand for services with an accompanying increase in Community Care costs, and that older persons might not want or be able to manage the payments themselves. Following national government review of Direct Payments, older persons became eligible for the program in 2000.

At the time of the site visit in October 2002, localities decided whether to offer Direct Payments to Community Care beneficiaries; since that date, the national government has required localities to offer Direct Payments. The localities also determine eligibility, user charges, payment rates, and other aspects of Community Care and Direct Payments under broad national guidelines. This flexibility has resulted in a great deal of variation among localities' programs. Partially in reaction to this variation, England's Department of Health recently began tightening some of the standards localities must meet under Direct Payments.

Another major challenge for Direct Payments has been how slow localities have been to offer the program to Community Care users.† Most of the small number of people who “take up” Direct Payments are younger, physically disabled persons. Across England, only about 8,000 Community Care users have Direct Payments, and only 13.1 percent are age 65 and older. These

* People with disabilities in England prefer use of the term, “disabled people,” because they believe it is society that disables them with its lack of accommodation to their special circumstances. Therefore, this case study of Direct Payments in England uses the terms, “disabled people or persons.”

† “Users” is the English term for participants in or beneficiaries of programs.

8,000 Direct Payments users represent about 2 percent of the 395,000 persons (381,000 households) receiving home care under the Community Care program in England.¹

Background

Home and community care in England has three major components:

1. The National Health Service provides some health-related long-term care, which local health authorities or trusts administer.
2. Several allowances provide cash payments to disabled people through the UK-wide social security benefits; the Department of Work and Pensions manages most of these disability allowances.
3. Elected local councils offer Community Care services, including homemaker and personal care services, adult day care, respite care, and group residential care, through their local SSDs, which administer a wide range of other social services. England's Department of Health oversees Community Care.

Until the advent of Direct Payments, the English long-term care system maintained a clear separation between paying people money through allowances at the national level and providing services at the local level.

National Health Service

The National Health Service's medically related long-term care primarily involves home nursing care as well as physical and occupational therapy, which are free of charge to permanent residents. Coordination between health and Community Care varies across England. Interviewees assert, and research² indicates, that few local health authorities coordinate their efforts well with local SSDs. The consequences for some disabled people who need health and long-term care in England is that these services may not be coordinated or not covered at all. Some Direct Payments users devote a portion of their funds to purchase health-related services such as physiotherapy because the local health authorities have withdrawn or have neglected to provide these types of services.³ Department of Health officials, however, have begun encouraging local health authorities and SSDs to pool budgets and, in some cases, to commission or provide services jointly.

Allowances

Three major UK-wide allowances are designed to help disabled people fund their care expenses. The Disability Living Allowance (DLA) is a Social Security benefit available to persons who apply before age 65, need help for at least three months because of a severe physical or mental disability, and are likely to need help for at least another six months. The DLA has a care component to help the disabled person pay for services and a mobility component to help defray transportation costs. In 2002, the care component ranged from £14.90 to £56.25 a week, and the mobility component ranged from £14.90 to £39.30 a week, depending on the severity of the disability. The Attendance Allowance (AA) is available to those age 65 and

over who need constant care at home for at least six months. In 2002, the AA amount ranged from £37.65 to £56.25 a week; there is no mobility component to this allowance. According to Department of Health officials, about two million people received the DLA and 1.3 million received the AA in 2002 (people cannot receive both allowances concurrently). The DLA cost £6.185 and the AA cost £3.215 billion in fiscal year 2003.⁴ Furthermore, according to departmental officials, about one-third of DLA recipients and half of AA recipients receive Community Care.

The Independent Living Fund (ILF), established in 1988, was initially designed as an allowance to “top up” the community care services available through the localities; it continues to perform this function. The fund provided non-means-tested cash payments to disabled adults who met its eligibility requirements. However, in 1992, the government limited new applications to persons age 65 or younger and began to means test benefits because, according to stakeholders, of the rapid growth in fund disbursements.

Currently, adults are eligible for the ILF if they: (1) apply before age 65, (2) receive £200–£500 a week of Community Care from their localities’ SSDs, (3) receive the highest care component of the DLA, and (4) have no more than £18,500 in assets, excluding their home. This same asset test applies to couples. The payment amount is determined by the number of hours of care a person needs and the cost per hour of care, minus the amount of income the fund requires the beneficiary to contribute toward the cost of services. Beneficiaries have to use fund payments for services from an individual worker or agency, and beneficiaries must maintain records of how they use their payments; however, these records are rarely audited. According to Department of Health officials, the fund served about 15,000 disabled people at a cost of £127 million in fiscal year 2000.

Community Care

In England, the national government gives localities annual social services grants, which localities use to provide a wide range of social services, including Community Care. Community Care provides home and community services for disabled adults and frail older persons as well as placement in group residential settings, including nursing homes. According to interviewees, social services grants have declined in real terms over the past decade; however, the national government has announced plans to increase the social services grants from £9.231 billion in fiscal year 2003 to £11.856 billion in fiscal year 2006. This increase is projected to be about 6 percent a year above the general inflation rate in those years.⁵ In addition to general social services grants, local councils receive 12 separate grants targeted to specific social services; six of them are for children and families. According to the Social Policy Ageing Network, older persons accounted for about 62 percent of social services clients and 47 percent of gross social services expenditures in fiscal year 2000.⁶

Local councils are responsible for determining how much of the social services grant goes to the SSD for Community Care, then what part of Community Care funds are devoted to disabled adults and frail elderly persons. The localities control Community Care by determining eligibility criteria, assessment and care management processes, service plans, payment levels,

and quality assurance procedures, using very broad guidance from England's Department of Health. The norm for localities' SSDs is to have their employees directly provide Community Care or to contract out these services to private home care agencies.

Direct Payments

United Kingdom-wide Direct Payments legislation was passed in 1996 after about 15 years of advocacy at the local and national level by the younger, disabled population. Older persons were left out of the program initially because of policy makers' concern about cost escalation; moreover, advocates representing this group were largely absent from the debate because their primary focus was on fighting erosion of pension benefits and preserving Community Care services broadly. Over time, England's Department of Health broadened the scope of Direct Payments to include persons of any age with disabilities of any type, or who qualify for Community Care, and are capable of assuming the responsibilities of being an employer. Even carers (that is, informal caregivers) of disabled persons may receive Direct Payments for services that benefit them directly if their local SSDs make this opportunity available to them.

Evolution of the Program

Inspired by the Berkeley Independent Living experiment during the 1970s in the United States[‡], younger disabled people in England who were then living in residential care homes successfully pressured several SSDs in the early 1980s to let them move out of their institutions and into the community. These individuals used the payments that otherwise would have been made to care homes to purchase personal assistance. One of the first people to leave an institution was John Evans from Hampshire; he had become severely disabled in Berkeley and learned about the independent living movement while there. He adapted the concept of independent living by successfully advocating for direct payments, that is, payments that came directly to him. Other disabled persons were able to make similar arrangements with their SSDs. Some disabled persons negotiated "indirect payments" that were channeled through a third party. Under these arrangements, the SSDs paid the money to an independent, nonprofit agency, such as a charity or an independent living organization, which then paid the disabled persons' workers. According to interviewees, by the late 1980s, up to 12 localities had direct or indirect payment schemes that enabled disabled persons to hire personal assistants.

In 1992, the national government deemed the direct payment "schemes" (that is, arrangements) illegal because localities did not have explicit statutory authority to provide cash to Community Care users. As a result of this ruling, many of the localities with direct payment schemes began giving the payments to third-party organizations, such as Independent Living Centres, which managed them for disabled persons. By 1994, the Policy Studies Institute found

[‡] The experiment involved several students with severe disabilities who attended the University of California at Berkeley while living together in shared housing with personal assistance services. This was remarkable at the time because most of their peers with this level of disability were confined to institutions without the opportunity to attend a university or live independently.

that 60 percent of SSDs responding to a mail survey in England, Scotland, and Wales allowed disabled users to hire individual workers, usually through an indirect payment mechanism.⁷

Key leaders of the Association of Directors of Social Services were supportive of Direct Payments and used their political connections to get the ear of the then-Conservative government. In 1992, the association passed a resolution asking the national government to give localities explicit authority to provide direct payments to people with physical disabilities. Although the association supported Direct Payments, it feared SSDs could be overwhelmed by an avalanche of new requests for the program, and localities would have difficulty in meeting the needs of users and their personal assistants as they negotiated this new approach to Community Care. Thus, the association advocated a gradual approach to implementing the legislation. Some localities resisted the legislation because they feared users would misuse the cash and localities would still be legally obligated to provide community care.

The Conservative government initially resisted Direct Payments because of cost concerns. The Treasury Department, in particular, feared high demand for Direct Payments based on rapid growth of the Independent Living Fund in the late 1980s and early 1990s.

By 1995, however, the Conservative government was listening to the arguments of Direct Payments' advocates. According to some respondents, the government began to see Direct Payments as a way to privatize services, provide more choice to users, and perhaps reduce community care costs. This cost-containment argument was given a push by a study of use of the Independent Living Fund by Jerry Zarb and Pam Nadash that showed cost savings for people handling their own payments.⁸ According to some interviewees, this study appeared to tip the balance in favor of Direct Payments, which passed in 1996 and was implemented in April 1997. The original legislation included people with learning difficulties but excluded older persons. However, the legislation gave the national government the right to reconsider the issue and extend Direct Payments to this population by issuing new "guidance" (that is, regulation).

Members of the Labour government, which came to power in 1997, generally had two positions on Direct Payments. More traditional Labour politicians believed Direct Payments threatened the jobs of local government workers. However, "New Labour" supported Direct Payments because it wanted to foster modernization and choice and reduce bureaucracy. The Labour government originally did not want to make the program mandatory because local councils are elected bodies with the right to fund and make decisions about Community Care.

With the support of the Labour Party, England's Department of Health extended Direct Payments to persons age 65 and over in February 2000. Disabled children age 16 and 17 as well as parents of disabled children received the ability to have Direct Payments as part of The Carers and Disabled Children Act of 2000. The Health and Social Care Act of 2001 requires localities to offer Direct Payments to persons with all types of disabilities who receive Community Care, including those with mental health conditions. This act also expanded the permitted uses of Direct Payments so disabled parents could use these funds to purchase assistance with managing their parental responsibilities.

Eligibility for Direct Payments

Each locality determines its own financial and functional eligibility criteria for Community Care; in practice, according to stakeholders, those with severe disabilities are most likely to be deemed eligible because of budget constraints. If a person is eligible for Community Care, then he or she can request Direct Payments. In general, Direct Payments is available to disabled people age 16 and over with any kind of impairment or a disabling illness such as mental illness or HIV/AIDS; the disability may be short- or long-term. Users must be able to manage the Direct Payments, either alone or with assistance, which can involve someone with power of attorney, a carer, or some other type of third party helping the user with his or her responsibilities as an employer. However, the user remains accountable for how funding is spent. Users also can set up an “enduring power of attorney,” which gives someone control over financial matters, including Direct Payments, after the user has lost mental capacity.

People with mental health conditions cannot receive Direct Payments if a court has ordered their treatment, because in theory these people are not capable of managing their own services. According to interviewees, compulsory mental health care is common in England.

The localities also can make Direct Payments available to carers if they are: (1) parents who need support to continue to provide a substantial amount of care regularly to a child, or (2) age 16 or older and provide a substantial amount of care to someone age 18 or older who is eligible for Community Care. Carers must use these payments only for services they themselves need such as transportation to the disabled person’s home. Localities are not obligated to provide services to carers.

Administration

The national government imposes few rules on administration of Direct Payments, but it does issue policy and practice guidance that localities follow in providing their Community Care and Direct Payments. Policy guidance generally is binding on localities. Practice guidance often accompanies policy guidance and contains recommendations localities are expected to follow but can modify as needed. Little information is available about how much nonmandatory guidance localities adopt, and, according to interviewees, the variation is quite substantial in England’s 150 localities.

At the time of the site visit, localities determined whether to offer Direct Payments, and care managers have a great deal of control over which users receive information about the Direct Payments option. However, in August 2002, the English government issued draft mandatory policy guidance requiring all localities and care managers to offer the Direct Payments option to all Community Care users deemed capable of managing it, with or without assistance. In addition, the August guidance proposed new rules for localities to follow regarding eligibility determination, care management, and charging (that is, copayments). These proposed rules became mandatory April 1, 2003.

Eligibility Determination

All localities control eligibility standards for Community Care and have a duty to assess a person's need for services. Until recently, localities had few national requirements regarding their assessments except that functional assessments had to precede financial assessments.

In response to the considerable variation in eligibility standards, the national government issued mandatory policy, called Fair Access to Care Services, in 2002, which required localities to use certain principles when determining eligibility by April 7, 2003.⁹ Within a locality, users with similar levels of disability are to receive services designed to achieve similar outcomes; this provision is supposed to ensure more uniformity in eligibility determination and provision of services to people in the same locality. Social services departments' needs assessments are to be designed to determine the applicants' level of risk if they do not receive services; the assessments are to include four levels of risk—low, moderate, substantial, and critical. Low risk is when an applicant might not be able to carry out one or two personal tasks or familial or social roles without Community Care. Critical risk is when the applicant would be at risk of serious harm or abuse without services. Risk to a person's independence, health, safety, personal or domestic routines, social and family relationships, and roles and responsibilities is taken into account during the assessment.

In March 2001, the Department of Health issued policy guidance requiring a single assessment for older persons;¹⁰ this was done to reduce the number of assessments a person must undergo and to help speed up and coordinate provision of health and community care. The assessment must be available at four levels: basic, complex, specialist, and comprehensive. Those who receive services in the NHS receive a health assessment and then are referred to SSDs for a social services assessment, if necessary. The applicant's needs determine which of the four levels of assessment he or she receives. In addition, any assessment must take into account the informal carer's ability to provide services. By the end of 2004, assessments will have to begin within 48 hours of a request and must be completed within one month.

The Carers and Disabled Children's Act of 2000 entitles carers to assessments on request, but localities have no duty or obligation to provide services as they do for disabled people who meet eligibility requirements. According to advocacy groups, only a minority of localities provide services that the carers' assessments recommend.

Care Management and Service Plans

Care managers are an integral component of the Direct Payments process because they devise the service package. Based on the assessment of need, care managers generally list the services a user needs and translate these tasks into hours of service per day. The locality attaches a monetary value to these services for persons who choose Direct Payments; the value must be sufficient to enable the user to legally secure adequate-quality services. According to Social Care Institute for Excellence (SCIE) staff, per hour wages for daytime care range from around £5 to £8.50. The range of rates in London is higher—£6.50 to £9.00 an hour. These payments generally must cover the workers' wages as well as the cost of employer taxes, four weeks' paid

holidays, sick pay, recruitment, and training. As a comparison, the minimum wage in England at the time of the site visit was £4.20 per hour, and the average wage for a cleaner was £5.35 an hour.

Although England has no nationally determined maximum or minimum Direct Payment amounts, payments are not supposed to exceed the cost of residential care for a disabled user. Payment rates for homes for older persons are much lower than rates for homes for younger adults and for those with learning difficulties.

For several reasons, according to interviewees, there can be large disparities in the number of services a younger person receives compared to an older person with a similar level of disability. First, some localities assume younger persons need to have as much integration into the community as possible. Second, people with learning difficulties tend to have the highest ceilings on their care packages, followed by younger, physically disabled population, and, at the bottom, the frail older population; thus limits on care packages may be lowest for older persons. Third, the equity in a person's home is counted as an asset when determining eligibility for means-tested residential care, so people have to sell their homes and use the proceeds to pay for their institutional care before localities have to take on this cost. Since older persons may be more likely to own their own homes than younger people, the cost of institutionalizing an older person may be lower for a locality than institutional care would be for other populations with disabilities.

Service Charges

Until recently, localities also have had complete control over user charges (that is, copayment) for services for Community Care and Direct Payments. Almost all localities have imposed some sort of charge, but the type and amount of charges vary greatly. As a result, the national government issued practice guidance that advises localities not to reduce income through charges below the level of England's Income Support program plus 25 percent.¹¹ Users with incomes above a locality-set level must pay for all of their services.

How users pay service charges has been controversial. Many localities deduct service charges from the Direct Payments amount, then give the balance to the user. In the long run, some users have complained they do not understand the extent to which they are paying charges and prefer to pay the charges separately. Interviewees said that, in general, localities prefer to deduct the charges up front because they have no easy mechanism for collecting the charges from users, but some SSDs have accommodated users' preferences by collecting charges separately.

Adoption of Direct Payments by Beneficiaries

In general, advocates for Direct Payments say, and available research¹² indicates, the program increases disabled persons' control over their lives and encourages services more tailored to their needs. Advocates assert that local bureaucracy is reduced because demand for local government agency workers decreases. Opponents of Direct Payments express doubt that

disabled people can handle the employer paperwork requirements or fear the option might be abused at the hands of their workers. They also express concern that local government workers would lose their jobs, and expenditures could be high because of the demand for cash.

The major challenge the Direct Payments program faces is Community Care users' very low rate of adoption of this option. Obstacles include the initial reluctance of many localities to offer Direct Payments as well as care managers' and some users' lack of knowledge about and reluctance to accept Direct Payments.¹³ The national government has responded by issuing mandatory policy guidance requiring that Direct Payments be offered as a choice to every Community Care user who qualifies, beginning April 2003.

According to interviewees, many localities, particularly those in the north of England, have been slow to adopt Direct Payments after it passed in 1996. By 2000, however, 80 percent had introduced Direct Payments, with adoption still higher in London and lower in northern localities. Most localities without Direct Payments planned to introduce it in the future. By 2000, those localities with Direct Payments reported that 3,612 persons between the ages of 18 and 65 had exercised this option. Of the localities that had Direct Payments in place, 80 percent made this option available to people under age 65 with all types of impairments, including learning difficulties and mental health conditions.

Direct Payments were made available to older persons in 2000. According to Department of Health figures, by September 2002, only 7,882 people were Direct Payments users. Among users, 13.1 percent were age 65 and older.¹⁴ The percentage with learning difficulties was 9.3, while 1.6 percent had mental health conditions. About three percent of Direct Payment users were carers of disabled children. Furthermore, Hampshire and Essex were the localities with the most Direct Payment users, with more than 500 users each. Another 15 localities had 100 to 200 Direct Payment users; in contrast, 19 localities had 10 or fewer users.

Interviewees attributed slow take up to various factors, including (1) lack of knowledge about Direct Payments; (2) resistance by local officials and older people to diverging from the localities' traditional role as provider of services; (3) a protective attitude on the part of some local governments toward people with disabilities, particularly those who are elderly, frail, or have some type of mental health condition; and (4) localities' competing priorities.

Three audiences need to understand or be convinced about the feasibility of Direct Payments in each locality: the local council, which controls use of funds and sets policies for Community Care; SSDs' care managers, who help users to determine service plans; and the users themselves. Many of the second two groups are not familiar with Direct Payments unless there is an active group of younger, physically disabled users in the locality. Even if there is an active group, older users may not know about the option, in part, because of care managers' resistance to it.

Before Direct Payments were extended to older persons, care managers were interviewed as part of a pilot project that gave older persons choice over the agency or individual worker who provided services, with the locality retaining the role of employer.¹⁵ Interviews with the care

managers involved in the project revealed they had a protective attitude toward older people and did not offer the option to people they deemed unable to handle the choice. Older persons with cognitive impairments were considered to be particularly unlikely to be able to make choices. Also, some care managers believed the scheme increased their work burden because they had to spend extra time explaining the program to users and helping them to choose providers.

The results of several focus group discussions with older persons about the possible extension of Direct Payments to this group¹⁶ indicate that the bureaucratic burden of being an employer might be an obstacle. Participants in the focus groups also mentioned they would need information about Direct Payments and assistance with employer responsibilities. Fear that Direct Payments would mean a cutback in services was also a factor in the focus groups' doubts about the program, based on earlier experiences with localities' reductions in services.

According to interviewees, another set of issues affects take up of Direct Payments among minority populations. For example, many minorities may not speak English as their first language and the lack of educational materials in foreign languages can reduce the number of minorities who choose Direct Payments. In addition, some cultures frown on hiring female personal assistants because it is not considered appropriate for women to work outside the home.

Local officials asserted that there have been some major changes in their accountability processes since 1998, and a 1999 government audit of 10 localities backed up this assertion.¹⁷ In 1998, the national government began a move toward performance indicators for localities. Each locality receives an annual inspection to assess progress on a number of performance indicators, such as provision of services to carers, and on Direct Payments to users, which are part of the Performance Assessment Framework. Complying with these mandates, and vacancy rates of up to 15 percent for SSD staff, has slowed down implementation of programs such as Direct Payments. According to many observers, in many cases, localities simply do not have the necessary infrastructure to implement new programs aggressively.

Restrictions on Use of Direct Payments

Although there are few restrictions on use of Direct Payments, users must spend the money on services, and they are responsible for ensuring the services' quality and appropriateness. However, localities have a statutory responsibility to ensure that users get adequate services even if they misuse their funds. Thus, the government has imposed restrictions on Direct Payments designed to ensure their appropriate use. Users can hire private home care agencies or individual workers but not family members, except under extraordinary circumstances, such as residence in a rural area where few providers are available. However, Direct Payments cannot be used to purchase services from the locality's publicly funded home care agency. Direct Payments can be used to purchase care for short periods of time in a residential care facility, but for no more than four weeks in a given period.

Financial monitoring varies among the localities. Most follow the practice guidance that recommends that Direct Payments users set up separate bank accounts for their payments for localities to audit. Workers typically fill out time sheets documenting their provision of services,

which users sign. None of those interviewed remarked fraud was a problem with Direct Payments, nor did a pilot project of Direct Payments in one locality find any incidents of abuse, financial or otherwise.¹⁸ Some interviewees mentioned that some localities' auditing costs are high.

Advocates of Direct Payments pointed out that labor laws in England are so complicated that most disabled persons need some assistance and education in managing their responsibilities as employers. Currently, the national government is examining whether to require local support centers for Direct Payments users. Some localities have such centers, but they are not mandatory. These centers may help users to recruit workers, provide lists of workers who can offer backup services during emergencies or holidays, and help with payroll and other administrative requirements.

Labor Issues

There are two major labor issues surrounding Direct Payments: very broad restrictions on disabled users hiring relatives to provide care, and, according to some interviewees, a labor shortage resulting from low wages and lack of union protection. Users cannot hire married or unmarried partners who live in the same household, and there are no exceptions to this rule. Close relatives (parents, parents-in-law, aunts, uncles, grandparents, sons, daughters, sons-in-law, daughters-in-law, stepsons or -daughters, siblings, or partners of any of these people) also are not supposed to be employees.

These restrictions are in place for several reasons. When the national government implemented Direct Payments, it wanted to avoid replacing informal support networks. There is concern that it would be hard to enforce an employment contract between relatives, particularly if the family sees Direct Payments as a source of family income. Younger, disabled people also resisted the idea of having to rely on family; they would rather set up their own independent households and have workers who are accountable to them as employers.

While these restrictions are generally not controversial among advocates, available research indicates that inability to hire relatives may be an obstacle for older people. Focus group research¹⁹ and interviews with older persons²⁰ indicate that this group would want to hire family members, in part because they fear strangers entering their homes or because they want to help support the efforts of their unpaid carers. Among minority communities, the ability to hire family is considered important, because minorities are thought to want someone from their own community who can provide culturally appropriate services. As a result, some interviewees said, implementing the prohibitions against hiring relatives has been somewhat flexible for minorities.

Most stakeholders agreed there is a general shortage of workers available in the long-term care market, which has led to some Direct Payments users having difficulty in recruiting personal assistants.²¹ The problems seem particularly acute in the southern part of England, where unemployment is quite low and housing costs are high, so few low-wage workers are available locally.

Stakeholders pointed out some of the differences in employment among individual workers under Direct Payments, those in private home care agencies, and SSDs' home care agency employees with union protection. Individual workers have more flexibility to negotiate schedules and tasks than either type of agency workers; agency workers benefit from the support available from their peers; and SSD home care agency workers benefit from union protection against arbitrary decisions by users, access to private pensions, and payment for travel time and costs as well time spent in training. Another issue arises when Direct Payment users resist workers' use of mechanical equipment in the caring process. Some stakeholders assert that lack of equipment could lead to unnecessary worker injury; other stakeholders question this assertion.

No information appears to be available on the differences, if any, in wages among SSD, private agency, and Direct Payments workers. Eighty-two percent of SSD workers surveyed in December 2000 made less than £5.57 an hour, with some earning as little as £4.00.²² These rates are not substantially different from the hourly payments Direct Payments users receive to pay their workers. Unions believe Direct Payments is exacerbating the loss of unionized jobs in SSDs that employ in-house agency workers to provide Community Care. Localities in many areas of England have been privatizing their workforce and hiring private companies to provide Community Care, thus reducing the number of union workers.

Cost Containment

Most observers agreed localities' budgets have been under pressure since the 1980s. In response, localities have minimized costs by tightening up eligibility standards, imposing service charges, and narrowing the range of services they provide.²³ For example, many localities do not pay readily for homemaker services for people who need only this type of service.²⁴ According to some interviewees, in the past, some localities set up waiting lists for assessments and services as a means of containing costs. These lists are not permitted now.

Some localities have cut off services to current users due to budget constraints; however, those users have successfully challenged the localities because the latter have not proven a change in the user's condition. As a consequence, localities are not supposed to cut off or reduce services for budgetary reasons without reassessing the user's needs first.

Quality Assurance

Users must ensure the quality of the services they receive under Direct Payments through their supervision of their workers. Care managers assess users' situations six weeks after services begin, again at six months, then once a year thereafter to ensure they are receiving the services they need.

At present, Direct Payments workers do not have to meet any standards beyond those the user requires. There is some debate about whether individual workers should meet the new national standards that agency workers must meet and be listed on a registry. At the time of the site visit, advocates had successfully avoided pressure to regulate workers because younger users

want to main control over their workers' training and selection. Criminal background checks for workers are only required for those serving children or youth under age 18.

Endnotes

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GERMANY'S EXPERIENCE WITH CASH PAYMENTS

Alison Evans Cuellar, Ph.D.

Background

Germany is already a relatively “old” country, and the proportion of the population age 60 and older is estimated to increase from 22.5 percent in 2000 to 34.0 percent in 2030.¹ The population over age 80, 32 percent of whom require long-term care services, is expected to grow even faster.² These demographic trends are likely to create challenges for the country’s health and long-term care programs.

The German long-term care social insurance program, called “Soziale Pflegeversicherung,” enacted in 1994, provides extensive coverage of both home care and nursing home services for people of all ages, regardless of financial status. The program was implemented quickly, with surprisingly few difficulties, and, after eight years, it maintains broad popular and political support.

The program is administered by “sickness funds” which are quasi-public, self-governed insurers heavily regulated by the national government.³ These are the same sickness funds that administer the acute care health program. As in acute care, sickness funds receive long-term care contributions, negotiate with providers, make payments, and participate in setting quality standards. They also sponsor the medical offices, one for each of the *Laender* (roughly the equivalent of states in the United States), that assess long-term care beneficiaries for eligibility.

When applying for eligibility, beneficiaries select either institutional or home care. Within the home care component, individuals are given a choice of spending a fixed amount on formal services or receiving a lower, fixed amount of cash. Although there is considerable flexibility in using the service benefit (the term used for agency-provided services), the cash benefit is more consistent with the term, “consumer-directed” care, used in the United States. Unlike the United States, the cash benefit option in Germany did not arise from a strong consumer or independent living movement. Instead, the overall goal was to introduce some sort of social insurance for long-term care and to largely replace the welfare-based social assistance program. Implementation of long-term care insurance has made coverage for such care more like that of a medical care program, although medical care has more generous coverage and no preset limits. When designing the long-term care program, the cash benefit option was considered to be a more socially desirable way to stabilize families and avert institutionalization than offering service benefits; furthermore, it was viewed as a cheaper alternative. Ultimately, beneficiaries have expressed a strong preference for family-based informal care and even more have chosen the cash benefits than was originally estimated.

Although administered by the same sickness funds that administer acute care, long-term care is fiscally separate from acute care. The program is financed by a nationally uniform payroll tax legislatively set at 1.7 percent of salary, which is shared equally by employers and employees.⁴ Retirees pay half the payroll tax amount, while their pension funds pay the other half.

The program has already achieved many of its goals, including shifting the financial burden of long-term care away from the Laender and municipalities, expanding home and community-based services, supporting persons with long-term care needs, bolstering family caregiving, and lessening dependence on means-tested welfare.

Current policy developments and debates surrounding long-term care now focus on (1) improving the status of informal and formal caregivers, (2) developing quality assessment and improvement systems, (3) incorporating consumer perspectives, and (4) addressing the needs of particular populations, such as persons with mental disorders. While there is general agreement on the direction that improvements should take, specific reforms in these areas to date have either been modest or encountered strong resistance. Generally speaking, attention to consumer involvement and quality in institutional care receives more attention than quality in home care.⁵ One major constraint is available financing. Because of the markedly aging German population, the program has steadily served more people and, ultimately, expenditures are projected to exceed contributions, barring further legislative changes.

This chapter reviews the major structures of the German long-term insurance program with special emphasis on home care, provided formally and informally, rather than on institutional care. Within home care, it focuses on the ability of consumers to choose and direct care, through both the services benefit and cash benefit options. It highlights areas of recent reform and debate, focusing on eligibility and assessment, benefits, labor supply and availability of services, quality assurance, and long-term financial outlook.

Home Care Benefit

Two guiding principles of the program are to promote care at home over institutional care and to recognize the important role of informal caregiving in long-term care. When the program was implemented, home care benefits became available first, followed a year later by nursing home benefits. The program is intended to support the willingness of families, friends, and volunteers to provide care, so beneficiaries can stay at home as long as possible. The program provides financial and caregiving relief to beneficiaries and families but explicitly does not cover the full cost of care.

When applying for eligibility, beneficiaries in the community choose between a fixed amount for formal services or a lower, fixed amount of cash. They may choose the cash benefit, as long as care is “secured,” that is, a caregiver is in place. There are no limitations on who may choose cash benefits (for example, persons with severe cognitive impairment), but anyone electing cash receives regular “control” visits from a provider to confirm that care is in place. Consumers electing the services benefit select from among paid services offered by local agencies, while those choosing the cash benefit rely mostly on unpaid informal care.

Eligibility Requirements

In 2001, the total number of beneficiaries receiving either home care or institutional services through sickness funds or private insurance was 1.9 million, roughly equal to the

number of people originally estimated to be eligible based on extensive household sample surveys.⁶ The program serves approximately 8.6 percent of the total population over age 60.

Eligibility is limited to persons of any age with relatively severe disabilities. Benefits are based on three levels of disability, which depend strictly on functional status, specifically the time required for specific activities of daily living (ADLs) and instrumental activities of daily living (IADLs) (Table 1; all tables appear at the end of this case study). By federal law, persons are eligible if they have a mental or physical condition that results in the need for assistance with ADLs and is expected to last at least six months. No social assessments are used. Consequently, eligibility and benefits are completely independent of family caregiving availability and arrangements. The minimum threshold for obtaining benefits is limitations in two ADLs and need for help in some IADLs for at least 90 minutes a day.⁷ Need for medical care is not taken into account. Table 1 shows the proportion of beneficiaries in each eligibility category. As expected, persons electing care at home are less disabled on average than are persons in institutions, but the differences are not huge. There is no evidence that individuals are able to game the assessment process, that is, applicants are not consistently being assessed at higher disability levels as the program matures.

Three eligibility categories determine the level of benefits for institutional and noninstitutional care (Table 2).⁸ Generally speaking, persons at the lowest level of disability have more difficulties with personal hygiene than mobility and their basic needs can be met with a single, daily intervention. At the middle level of disability, typical persons cannot address their own personal hygiene needs, feeding, or mobility. Consequently, care is typically needed many times each day. At the highest disability level, persons typically need help at varied times around-the-clock.

After many years of debate, persons with dementia or other mental or developmental disabilities who live in the community and require general supervision (for example, due to a tendency to wander off, inability to recognize dangerous situations, or severe depression) are eligible for a small additional benefit.⁹ Effective in 2002, the program added a small, additional respite benefit for the estimated 550,000 beneficiaries with dementia or other mental or developmental impairment to provide relief for their caregivers. The expansion was modest (estimated at 280 million Euros, or 460 Euros per beneficiary per year) and was instituted primarily to acknowledge the concerns of beneficiaries with these conditions but without causing a significant financial burden to the program.

Benefits

Given a choice between institutional and home care, the overwhelming majority of beneficiaries, 70 percent in 2001, choose care outside of nursing facilities (Table 3), consistent with one of the program's major goals. This proportion is down only slightly from 73 percent in 1997 (the first full year both home and institutional care were available).

For people living in the community, an innovative provision is the consumer's choice between receiving services up to a monthly capped cost or receiving a lesser amount of cash. The maximum service expenditure per person in the community is capped at levels that vary by

disability level (Table 4). The cash levels are a bit less than half the cost of the service benefits. Beneficiaries can elect to receive part of the service benefit, and any unused portion is paid out as a prorated amount in cash. The higher their disability level, the more likely it is for beneficiaries to choose this “combination benefit.” In addition, some assistive devices and home modifications, up to a cost of 2,557 Euros (roughly \$2,557) per modification, are covered.

As stated above, any beneficiary who meets the criterion of requiring significant general supervision due to dementia or mental or developmental impairment may receive an additional 460 Euros a year. The amount is independent of their disability level or whether they choose cash or services. The benefit is available only to reimburse beneficiaries for specific services, geared toward providing respite to caregivers. The funds must be used for partial day or night care, short-term institutional care, agency services for general supervision, or local program services for persons with dementia; the money is not to be used for ADL or IADL assistance. The new law also commits 20 million Euros to developing new programs where volunteers, under the supervision of trained elder care workers, assist persons with dementia in group or home settings. This program is based on some families’ greater willingness to ask for assistance from volunteers than from formal, paid service providers.¹⁰

There have been only minor adjustments to the benefits since the program’s inception, but the changes, such as they are, addressed the areas of greatest consumer concern. Before recent benefit expansions, most consumers reported being either satisfied or very satisfied with the level of the benefit (66 percent), rather than unsatisfied or very unsatisfied (31 percent).¹¹ The unsatisfied consumers tended to be those whose family member had dementia, was using partial day institutional care, and whose informal caregiver felt heavily burdened. The relatively modest legislative changes since the survey included increasing the benefit for partial day or night care for levels II and III and adding a benefit for persons with dementia.

The program spends only up to a preset monthly amount per person. Consequently, program expenditures per beneficiary depend solely on disability level and whether a person chooses services or cash, not on the number of services a person uses or provider payment levels. There are no regional adjustments to the benefits, such as higher payments for urban versus rural areas. Because there also are no inflation adjustments, the benefit has eroded over time. The erosion in benefits for consumers choosing services has been limited by the fact that negotiated provider rate increases have been relatively small. Over the five years from 1998 to 2002, providers in a quarter of Laender reported no increase, and another quarter had a total increase of less than 5 percent. Only two of 16 Laender had increases of 10 percent or more over the five years. However, regional differences at any point are greater than differences in purchasing power over time. To illustrate, a person living in the Schleswig-Holstein, in the former West Germany, can expect to pay 25 percent more than a person living in Saarland, in the former East Germany, for assistance with eating.¹²

Administration

Eligibility Determination

Assessments are conducted by the medical offices of the sickness funds, and average eligibility determinations takes two months.¹³ Most consumers are satisfied with the sickness funds' customer service as well as with the medical offices' assessment decision.¹⁴ Among those designated as level I, however, 32 percent were not satisfied with the medical office's decision and felt they should have been assigned to a higher disability category, whereas only 9 percent of those designated as level III were not satisfied.¹⁵ Given that eligibility criteria are relatively inflexible, focusing specifically on time spent on ADLs and IADLs, it is not surprising that dissatisfied beneficiaries report the assessment is overly standardized and does not take into account their specific needs.¹⁶

According to consumer surveys, doctors play a large role in informing beneficiaries about the long-term care program and recommending application.¹⁷ Almost equally important are the media, followed by friends, and, last, the sickness funds. Consumers elect cash or service benefits at the time of eligibility application; however, they receive little formal guidance when making that choice. A recent change in the law makes minor changes with the potential to assist beneficiaries. Under the new law, beneficiaries may ask that a family member or a representative from a home care agency be present at the assessment. Further, assessments must be performed in person and cannot be completed on the basis of documentation alone.¹⁸

If their health deteriorates, beneficiaries can reapply to the medical office to be assessed for a higher disability level. In fact, 30 percent of medical office assessments are reassessments of this kind. However, no specific institution or consumer agency is formally charged with assisting beneficiaries in requesting this reassessment, and there are no studies of whether this occurs. Presumably, service providers making "control" visits can advise clients when their health has deteriorated and recommend a reassessment.

Provider Contracting and Payment Rates

Providers participating in the long-term care program must contract with the sickness funds that will reimburse them, not the clients. In other words, contract terms, such as payment rates and quality standards, are negotiated between providers and sickness funds, not consumers. Consumers with the service benefit may select among all the available contracting providers in the area, but they have no way of contractually specifying such things as a specific caregiver from a particular agency.

Nationally, the sickness fund and provider associations have devised approximately 20 service "bundles" (for example, brief morning and evening visits that include dressing and undressing, partial washing, brushing teeth, and combing hair) that are assigned weights and form the basis for payment for 80 percent of home care providers. The other providers are paid based on the number of services or the amount of time.¹⁹ Providers affiliated with charitable organizations negotiate uniform reimbursement rates for the service bundles collectively with

sickness funds at the Laender level. Thus, there is no price competition across charitable providers. Independent, private providers negotiate rates individually with sickness funds. However, private providers increasingly are joining associations that negotiate collective rates and contract terms on their behalf. Sickness fund respondents noted that this trend toward higher association membership had contributed to the overall bargaining skill of providers and to the increasing pressure to raise rates. Under the new Long-term Care Quality Assurance Law of 2001, sickness funds are able to review providers' quality results when negotiating rates. This creates an opportunity to incorporate quality measures into rate negotiations in a more systematic fashion than was possible before the law was passed.

Beneficiaries

Among the community-based population, a substantial majority—71 percent—chooses cash rather than services (Table 5), but the proportion of beneficiaries choosing formal home care services or a combination of services and cash has increased. Those who elect the cash benefit tend to be less disabled,²⁰ younger, have a caregiver who is a spouse or child, and have more support (formal and informal) available to them than persons who elect the service benefit.²¹ In 1998, 82 percent of beneficiaries at level I chose cash, compared to 77 percent at level II and 64 percent at level III.

Persons living alone were only somewhat less likely (seven percentage points) to choose cash than was the average beneficiary living at home.²² In part, this reflects the fact that persons living alone at home are less disabled and less likely to have mental disorders than are other beneficiaries.

Dementia is not a reason to deny cash or to require services, although recent changes provide incentives for caregivers to receive more respite. The cash benefit is not necessarily paid directly to the beneficiary, however.²³ Some beneficiaries may have a designated legal representative who manages their affairs and receives funds on their behalf. In many cases, this representative is likely to be a family member.²⁴

According to national survey data, consumers elect cash because it is needed for ongoing long-term care costs (88 percent) and because they prefer to receive care from family and friends rather than strangers (87 percent).²⁵ Beneficiaries rarely reported having to choose informal care because professional services were not available locally. In the same survey, 90 percent of those choosing services responded that the poor health of the beneficiary made professional services unavoidable, or that the medical office has recommended the services. Another 73 percent said informal caregivers were overburdened, and 65 percent said they did not want to burden their caregivers even more. Persons with the combination benefit primarily reported they wanted to have cash available for ongoing long-term care expenses, greater flexibility, and the ability to pay private caregivers a small amount.

A separate local study found that the most important reasons for persons electing service benefits over cash benefits were because family or friends were becoming too burdened (53 percent of respondents) and because of the professional nature of the needed services (51 percent).²⁶ However, those choosing service benefits reported having more difficulty organizing

their care and having their needs taken seriously than did persons electing the cash benefit.²⁷ In contrast, those electing cash benefits said the most important reasons were to obtain assistance to meet individual needs (49 percent), to control own services (35 percent), to avoid having strangers in the home (25 percent), and to be able to pay the informal caregivers already in place (24 percent).

As there is no case management at the sickness fund level to aid in allocating the cash benefits, there is also no consistent case management at the individual client level to advocate for clients or to assist them in their choice of services. Typically, individuals and their families must decide about type of benefits (that is, nursing home, home care, or cash) and choice of provider on their own or with the help of a provider.²⁸ Once a provider makes a visit, the beneficiary and the provider agree on a service package. Under the new quality law, when a beneficiary elects services, the agency must draft a formal contract outlining exactly which services will be provided and how much they cost.²⁹

Since passage of the new long-term care quality assurance law, sickness funds must assist consumers, at least in a limited fashion, by helping them to choose services and providers if asked to do so. They may subcontract this advisory function to outside entities, as some currently do. Some people viewed the need for consumer assistance more broadly to include information on long-term care options, housing, health care, and other services. Such assistance generally is viewed as the responsibility of local communities, and some demonstration projects along these lines are being sponsored.

Services

Cash Option

Beneficiaries receiving cash benefits do not have to report how the funds are used, and there is no requirement that funds be used to buy long-term care services. Consequently, government officials do not worry about the benefit being “misused.” The main intent of the benefit is to promote care at home and to relieve family caregivers, not supplant them. In this sense, the cash benefit is like a retirement supplement, completely flexible, with the addition of regular “control” visits to ensure care is in place.

Beneficiaries may hire informal care providers; however, they must elect the cash benefit, not the service benefit, to do so. The service benefit may be used only for providers listed with the sickness funds. Providing long-term care is considered to be something family members do out of moral duty, not primarily to realize additional income. Consequently, any cash family members might receive for providing care is not taxed as income and is not counted toward eligibility for other programs, such as unemployment benefits.³⁰ The extent to which family members are paid for providing care is difficult to determine for several reasons: (1) often the funds are incorporated into the overall joint household budget; (2) funds may be transmitted to the beneficiary’s representative, who may also be the caregiving family member; and (3) payments to family caregivers may be made in-kind, rather than cash. Nonetheless, a local survey of 100 family caregivers found that half received a cash payment, typically a fixed monthly amount; in two-thirds of the cases the amount was equal to the full benefit amount.³¹

Cash beneficiaries rely on relatively little informal caregiving aside from family, so it is unlikely that cash is used for such services. In a local survey, only 16 percent of beneficiaries reported any informal assistance outside of family and neighbors.³² Parties can formalize their informal caregiving arrangement by having the caregiver work as an independent employee or establish a “stand-alone agency” and use the service benefit. Respondents believed these stand-alone agency arrangements were rare, perhaps existing only in rural areas that lacked other providers.

A small portion of the cash benefit is likely used for professional services, but only 11 percent of beneficiaries who elect the full cash benefit purchase any professional services at all (presumably these are services not covered by the long-term care program as described below).³³ In 1998, beneficiaries with cash benefits spent a mean of 125 Euros per month out-of-pocket for long-term care related services (including professional services and transportation, paying caregivers, assistive devices, special diets, and similar). The median amount is approximately 51 Euros per month, which is much lower because about a third of beneficiaries reported zero out-of-pocket costs.

Not all groups benefited from the cash option. Most observers felt that younger persons receiving personal assistance had actually been harmed by introducing cash benefits under social insurance because they replaced a more generous system under means-tested social assistance. Under the old social assistance program, persons wishing to live independently but requiring personal assistance services could arrange for their own caregivers and be reimbursed for the full cost of these services. Under the new program, however, only participating home care providers are permitted to receive reimbursement for services, and “laypersons” may not be reimbursed as service providers. Thus, the beneficiary must elect the cash option, which is not sufficient to cover round-the-clock care. After heated policy debate, 500 to 800 persons already receiving personal care through the old system were permitted to continue to do so with funding through social assistance.³⁴

Service Option

In the past eight years, use of service benefits and the combination benefits has increased, largely because of the higher proportion of applicants who are age 70 and over.³⁵ Persons electing home care services can receive a list of contracting providers from their sickness funds. Only specific ADL and IADL services are reimbursable by the sickness funds, namely those used in determining eligibility. Beneficiaries may receive assistance with personal hygiene (bathing, toileting, shaving, brushing teeth), eating (including food preparation), mobility (transferring in and out of bed, dressing, walking, standing, climbing stairs, leaving and returning home), and household activities (shopping, cooking, cleaning, washing clothes, washing dishes, and heating the home). As an alternative to the service option, beneficiaries can choose to receive care in partial-day or -night institutions, subject to the same benefit limits (see Table 4).

Consumers have an increasing number of provider choices. In 1992, there were roughly 4,300 agencies compared to 12,959 agencies in 2000, although growth has leveled off in some

regions.³⁶ No formal survey of demand has been conducted, yet supply appears to be adequate in most areas.

Historically, most home care providers were part of large social service organizations through charitable organizations, such as the Red Cross or various churches, and a small fraction were for-profit firms. However, most of the growth has been among small, for-profit agencies. In 1998 (the most recent year for which data were available), 4 percent of home care agencies were publicly owned, 52 percent were owned by charitable, nonprofit organizations, and 43 percent were private, for-profit organizations.³⁷ Ten percent of agencies were very small and served fewer than 10 clients, while the average agency served 44 clients.³⁸ The large organizations tend to offer more service choices. In a national survey, 44 percent of agencies, mostly larger, nonprofit providers, offered services to persons with AIDS, 54 percent to persons with severe mental illness, and 53 percent provided support services to persons with disabilities. Fewer than 45 percent of providers offered meals on wheels, laundry, or transportation.³⁹ Policy makers emphasize that recent funding made available for model programs will focus on the needs of targeted consumer groups, such as persons with dementia, brain damage, or physical disabilities.⁴⁰ Among reimbursed services (that is, specifically ADLs and IADLs assistance), most agencies spend the bulk of their time (53 percent) providing morning or evening personal care (transferring in/out of bed, bathing, changing cloths, and brushing teeth) and a smaller proportion on help around the home (heating or cleaning the home, laundry, shopping, and preparing meals).

Some beneficiaries (25 percent) receive professional services over and above what is covered by the service benefit.⁴¹ Beneficiaries who receive additional professional services tend to live alone or are younger persons with physical disabilities who receive volunteer services from disability organizations. These additional services are not necessarily paid for out-of-pocket. Some are financed by social assistance and some are provided on a volunteer basis (for example, meals on wheels). Nonetheless, a survey of agencies providing home care found that 18 percent of agency clients reportedly purchase services over and above the benefit amount.⁴² Another found the mean out-of-pocket expenditure for beneficiaries electing the service benefit was very close to that for beneficiaries seeking the cash benefit (131 Euros versus 125 Euros per month).⁴³ While social assistance beneficiaries who choose the home care service benefit are eligible for supplemental services if they need them, individuals who elect cash benefits are not eligible for any additional home care services; they would need to switch to the service benefit first to be eligible for social assistance.

Labor Force Issues

Informal Care

As in other countries, most long-term care is provided by family members—93 percent of primary caregivers are relatives, the remainder are neighbors or friends—and this has not changed significantly since the program's inception.⁴⁴ The family relationship of the primary caregiver to the beneficiary also has not changed significantly: 32 percent are spouses, 11 percent are mothers, 33 percent are daughters or daughters-in-law, 5 percent are sons, and 12 percent are other relatives. Other characteristics of caregivers also have been stable since before

the program began: 73 percent of primary caregivers live with the beneficiary; 68 percent of caregivers are under age 65; and, among those under age 65, 64 percent do not work outside the home.⁴⁵ The stability of caregiving patterns suggests that there has been no displacement of informal care through increased formal care as a result of the new program, but no increase in informal care, either.⁴⁶ To further the family caregiving goal (regardless of whether the beneficiary chooses the cash or service benefit), the program covers respite care for informal caregivers (up to four weeks), and pension credit is awarded to persons providing substantial levels of unpaid services who are not otherwise gainfully employed more than 30 hours per week.

In 1999, approximately 574,000 people (90 percent of whom were women) received pension credit as informal caregivers.⁴⁷ For pension purposes, informal caregivers are treated as if they earned 40 percent, 60 percent, or 80 percent of a reference salary⁴⁸, depending on the level and duration of care. The overall target is for persons providing at least 28 hours of care weekly at disability level III to receive 75 percent of the average pension payment. In 1998, the average amount of time an informal caregiver provided long-term care each week was 37.9 hours for level I beneficiaries, 49.5 hours for level II beneficiaries, and 60.6 hours for level III beneficiaries, although there is a wide range depending on how many caregivers are involved.⁴⁹ Thirty percent of nonelderly caregivers either gave up employment or reduced their work hours to provide care.

Despite introduction of the social insurance program, the proportion of caregivers who feel burdened remains 80 percent, although the proportion who feel “strongly burdened” declined from 48 percent to 40 percent between 1991 and 1998.⁵⁰ The caregiving burden is felt most strongly by those who provide care to persons with dementia, regardless of level of physical disability. There is also a strong correlation between feeling burdened and giving up a job to provide care.

The program has not led to major restructuring of households, for example, more parents moving in with their children. In nationally representative surveys, 22 percent of persons receiving care at home reported living alone, and this proportion is virtually unchanged since before the program began.⁵¹ However, fewer people with long-term care needs reported having no informal caregiver available since the program began (4 percent in 1998, compared to 9 percent in 1991). Furthermore, a larger proportion of individuals reported having more than one person providing their care informally (70 percent in 1998, compared to 63 percent in 1991).⁵² In a local survey, family caregivers were asked who coordinates care when multiple persons are involved.⁵³ Their responses indicate that beneficiaries play only a marginal role in determining who provides their care in such cases. Typically, the primary caregiver, not the beneficiary, determines when each caregiver works.

Formal Care

Home care providers, especially for-profits, tend to be small organizations; on average, agencies have 13 full time equivalent staff.⁵⁴ Of these, 39 percent work full-time and another 41 percent work enough part-time hours to qualify for social insurance benefits; the remaining 20 percent work just a few hours a week.

The number of persons employed in home health and home care continues to grow. From 1997 to 1999, and largely due to the long-term care program, there was a 12 percent increase in employed nurses, a 45 percent increase in qualified elder care workers, and a 13 percent increase in home care aides.⁵⁵ On average, agencies employ more skilled than nonskilled workers. In a national survey, agencies reported 52 percent of employees were trained nurses, another 17 percent were trained elder care workers, 10 percent had some other sort of formal training, such as aides, and the remainder had essentially no training.⁵⁶ The high ratio of skilled staff reflects the fact that 97 percent of agencies also provide home health services funded by the medical insurance program.

Surveys of workers in home care find that pressure to perform tasks quickly and physical burdens (for example, lifting and bending) were primary areas of workers' concern.⁵⁷ A third of workers surveyed felt "empty" or "burned out" as a result of working around persons near the end of life. Other pressures or concerns were working with persons with dementia, monotony of the tasks, and feeling underchallenged.

Despite the growing home health and home care labor force, policy makers and providers perceived problems with the educational system for elder care workers and home care aides, and extensive reforms were introduced in 2000. Most people interviewed for this paper believed the law was intended to raise the status and recognition of the elder care profession and to lead to greater interest in the currently undersubscribed training programs. With few exceptions, respondents did not anticipate that wages would rise significantly as a result of the revised training programs.

By tradition in Germany, "elder care" and "nursing care" are separate occupational categories for purposes of education and licensure. Whereas nursing care was a nationally well-defined occupational category, elder care ranged in skill from licensed practical nurses to registered nurses. The length, entry requirements, and curriculum for such training programs, as well as the scope of permitted practice, varied across the Laender, making it difficult for workers to move around. In 2000, Germany passed a law making educational requirements for elder care and home care aides uniform across the country.⁵⁸ Essentially, the law stipulates that training for elder care takes three years and more closely resembles the skill level of training for nurses. Goals of any elder care training program should include comprehensive long-term care (encompassing rehabilitation and pain management) and health care. Practical experience must include institutional and home or community settings. Finally, individuals in such training programs receive stipends, which was not uniformly the case in the past. For home care aides, training must be one year in length. Laender have more flexibility to define the curriculum for home care aides than for skilled elder care workers.

Cost Containment

One major goal of the new program is to spend more on long-term care overall and, at the same time, spend less through means-tested social assistance. Spending for the new program alone totaled 15.14 million Euros in 1997 and reached 16.87 million Euros in 2002 (Table 6). From 1991 to 1998, social assistance expenditures for home and community-based care declined

by 45 percent, while such expenditures for institutional care declined by 51 percent.⁵⁹ As of 1998, approximately 4 percent of persons receiving home care services received additional support through means-tested social assistance programs; this proportion has remained stable since 1998.⁶⁰ The program also substantially achieved its goal of expanding coverage of noninstitutional settings. About half of program expenditures are for noninstitutional settings, and 70 percent of beneficiaries live in noninstitutional settings.⁶¹ In contrast, most spending under social assistance before the new program went to institutional care.

After several years of building up surpluses, the program had slightly higher expenditures than contributions beginning in 1999; by 2002, however, the deficit was extremely small (less than 1 percent). The program has reserves equal to 25 percent of program expenditures. Higher costs are due to a gradually growing number of beneficiaries, the modest shift from lower-cost cash to higher-cost service benefits, and more people in higher eligibility categories. Minor benefit modifications, which recently took effect, will increase outlays further.

Despite a prolonged economic recession and high unemployment, policy discussions about cutting taxes or reducing public programs are not focused on long-term care, which is a relatively small program by German standards. Instead, these debates focus on long-range changes in health care and retirement programs. In fact, long-term care policy played virtually no role in the recent national elections, which focused mainly on foreign policy and recent recommendations of a national unemployment commission. While currently not a particular target for cutbacks, expansions of the long-term care program are considered unlikely.⁶²

The number of long-term care insurance beneficiaries is expected to rise from 1.9 million in 2001 to 2.3 million in 2010, a 20 percent increase. Projections show that if benefits were to increase by 1.5 percent per year nominally, which is less than the estimated annual increase in taxable wages, by 2030, the system could only be balanced if contributions increased to 2.1 percent of taxable salary, up from 1.7 percent today.⁶³ However, benefits are not indexed to inflation. Therefore, if no benefit adjustments are made for inflation, the projected increases in taxable wages could more than cover the cost of additional beneficiaries, at least through 2010.

The question remains whether beneficiaries and providers will be satisfied with small or no program increases. Beneficiaries were generally believed to be grateful for the program and its recognition of long-term care needs, particularly in light of current budget problems. Changes in the health insurance program, on the other hand, are considered politically sensitive. In the past, relatively small copayments for prescription drugs were introduced but had to be repealed due to voter backlash. In contrast, leaving long-term care benefits alone requires no actual change in the law; therefore, no policy debate would be triggered at any particular point. Whether the voter backlash to the health insurance change occurred because an active change was made to an entitlement program or because health insurance is a politically stronger force than the long-term care social insurance program is difficult to say.

Formal providers are only gradually showing displeasure at the slow growth in payment rates, and home care providers less so than institutional providers. Given the current economy and future demographic changes, there is strong awareness that any demands for program expansions are unlikely to succeed politically. Instead, providers are making the case that

quality improvements would have to come at a price. Providers, who were successful at blocking costly proposed accreditation procedures, also may be awaiting the outcome of the health insurance and retirement reform debates, because for many, a large fraction of revenues depends on the health insurance program.

Quality Assurance

By raising the status of long-term care from social assistance to social insurance, and by increasing visibility of long-term care in general, the new insurance program has sharply increased attention to quality as well. Policy makers agree that quality assurance has two major, formal components: (1) ongoing internal quality assurance activities conducted by staff members in agencies and (2) monitoring and certification activities by the medical office of sickness funds or similar third parties. Further, there is agreement that incorporating the perspective of beneficiaries and their families is important. There is less consensus, however, around who should research, develop, and define the prevailing quality standards as well as the assessment tools, assessment activities, and specific involvement of consumers. Much of the promotion of quality assurance is handled through coordinated activities of the sickness funds and incorporated into contracts with providers.

To date, most of the quality initiatives have focused on nursing home care. Scandals in nursing homes have been the focus of media attention, so quality in nursing homes receives the greatest public attention.⁶⁴ By comparison, defining and implementing quality standards in home and community-based care lags behind nursing homes. Least monitored is informal care provided at home, especially for people who opt for the cash benefit. Monitoring informal care requires balancing the program's consumer protection objectives against individuals and families' rights to autonomy and policy makers' desire to motivate families to provide care, rather than dissuade them.

Formal Care

A long-term care quality assurance law was passed in 2001, but some of the implementing regulations (June 2002) were blocked by the Laender because they were viewed as too bureaucratic and burdensome to providers. The new long-term care quality assurance law made several changes and required, for example that all agencies have a formal, internal quality management system that focuses on continuous quality improvement. This quality assurance system should encompass all employees and should address structure, process, and outcome dimensions of quality assurance. In addition, the new law made a range of sanctions available to sickness funds when quality problems are discovered, such as temporary reductions in payment rates, refunds, or temporary bans on client access. Previously, the only enforcement action available to sickness funds if they find poor-quality care is to terminate the participation contract.

Finally, much of the recent controversy surrounded the proposed requirements that all home care providers collect data for quality measurement and be accredited by newly formed, third-party expert organizations every two years, rather than at the current, slower pace. Currently, the medical offices conduct audits any time there is a complaint and randomly. As of 2001, 30 percent of home care and 62 percent of institutional providers had ever been reviewed.

At the current rate, approximately 20 percent of home care providers are inspected each year (equivalently, institutional providers are inspected every five years). The medical office seeks to have providers perceive the review process as consultative. Audits take two to three days and encompass structure, process, and outcome dimensions of quality. In addition, it is hoped that any required data and documentation will be useful for internal management and quality assurance purposes as well.

Providers generally do not have a positive outlook about the audit process, however; many viewed it as overly bureaucratic. From a consumer standpoint, there was concern that rigid quality procedures could make it more difficult for beneficiaries and their families to participate and make their own decisions regarding how care is provided.⁶⁵

Still lacking are quality standards that rely on outcomes rather than organizational structures or processes. Sickness funds have sponsored research on the development of consumer-focused quality criteria in nursing homes. One such study found that residents or their designated family members were able to respond to surveys in a meaningful way, that their responses helped to differentiate among providers, and that their criteria for high quality did not necessarily equate to a focus on credentials and technical skill in delivering ADL care, which is more typical of standards developed by other entities.⁶⁶ Instead, residents rated as important such things as being reminded of social activities and meetings, private rooms, quality and variety of meals, choice of one's own clothing, timeliness of response when calling for assistance, more time spent on caregiving, and more time for psychosocial interaction. Further, the study found little correlation between consumer satisfaction and the presence of a continuous quality improvement system or proportion of skilled staff at the nursing home.

Consumer satisfaction with formal in-home services in the community is relatively high. Consumer surveys find that most beneficiaries (80 percent) stay with their chosen provider and are satisfied with the care (72 percent).⁶⁷ In a national survey 72 percent agreed or strongly agreed that providers take time for personal conversations, while 28 percent disagreed or strongly disagreed.⁶⁸ Sixty one percent of consumers agreed or strongly agreed that providers take time to guide family caregivers, but 39 percent disagreed or strongly disagreed. Results from a local survey found that consumers who elected service benefits feel they have little input regarding who from the agency provides their services, at what times care is provided, and how it is provided.⁶⁹ Experts also have expressed concern that there is little coordination between agency and family caregivers and that instead the beneficiary is "handed off" without much dialogue.⁷⁰ Such lack of coordination prevents the sharing of information about beneficiaries' preferences, while also preventing agencies from recognizing family caregivers' need for respite early on.

Informal Care

While the quality of formal care is addressed in policy and legislative debates, the quality of informal care is another matter entirely, even when individuals receive a cash payment through the social insurance program. The prevailing view is that care among family members is a personal issue, largely outside the regulatory realm. For persons receiving cash, the initial medical office assessment and agency "control" visits paid by the sickness funds are the primary

quality-monitoring mechanism for informal and family care. Periodic “control” visits occur every four to six months, depending on disability level, to ensure the beneficiary is receiving adequate care. Because the control visits are performed by home care agencies, they may not be completely unbiased; providers may hesitate to alienate potential future clients.⁷¹ Some were concerned that providers would promote services the family did not particularly want or need. As part of the new quality initiatives, content of the control visits and provider responsibilities are being examined more closely and standardized. Previously, providers would note whether care was secured, and the family had to sign off. Now, providers are supposed to document what care is available and what additional care is suggested for areas where excessive burden is a concern.⁷² The sickness fund is then responsible for reviewing the suggestions and following up where it appears to be necessary. In keeping with the increasingly consultative intent of the visits, beneficiaries with mental disorders are permitted twice the normal number of control visits, if requested.

As shown in Table 1, more people with the most severe level of disability (which requires at least five hours of care, including nighttime) live in the community rather than in a nursing home, raising concern among some observers about adequacy and quality of care and family burnout. Some observers also saw a need for more attention to psychosocial issues within the family or caregiving group, rather than a narrow focus on the beneficiary’s physical needs. The sickness funds run educational classes on home care for informal caregivers, although these are not mandatory or very extensive. Survey results find that only 10 percent of informal caregivers have taken advantage of these courses. The low participation rate is attributed primarily to limited offerings and poor advertising by the sickness funds, rather than lack of consumer interest.⁷³

A wide range of policy experts perceive short-term and partial-day (or -night) care in institutions as underused. These services are promoted by the policy community on the basis that (1) formal care providers may be better able to improve beneficiaries’ conditions; (2) family care providers urgently need respite; and (3) early use of such service may prevent deterioration and the need for nursing home care.⁷⁴ Despite increasing the benefit for partial-day care and making creation of short-term and part-day beds a primary goal of federal grant programs, these services are not widely used.

Generally speaking, policy makers feel limited in what they can require in the family and informal care realm. They argue that neglect exists, but it is not caused or exacerbated by the long-term care program or its cash benefits. Family members should not be treated with distrust, since after all, those who take on caregiving are taking on a burdensome task that requires considerable personal commitment and presumably reflects a high degree of conscientiousness. Gerontologists and legal experts agree that monitoring the quality of informal care in the home is likely to be less effective.⁷⁵

The question remains by what mechanism any new outcomes research will be incorporated into the quality systems that are being implemented. Long-term care experts have voiced a preference for a more coordinated approach. They advocate for an independent, national council to develop evidence-based quality standards, which would apply consistently, regardless of whether the service is funded by the long-term care program, health insurance, or

social assistance.⁷⁶ They also advocate the use of evidence-based quality assessment instruments and standardized accreditation procedures and collection and dissemination of information on quality innovations and reports on progress in the field.

Tables

Table 1: Disability Categories in Social Insurance Program

Disability Level	ADL/IADL deficiencies	Frequency of assistance with ADL/IADL	Amount of assistance required for ADL/IADL
Level I: Substantial	Two or more ADL limitations and need for help with IADLs	ADL: At least once a day IADL: Several times a week.	Min. 90 minutes for combined ADLs and IADLs, with at least 45 minutes for ADLs
Level II: Severe	Two or more ADL limitations and need for help with IADLs	ADL: At least three times a day IADL: Several times a week	Min. 3 hours for combined ADLs and IADLs, with at least 2 hours for ADLs
Level III: Very Severe	Two or more ADL limitations and need for help with IADLs	ADL: Day and night IADL: Several times a week	Min. 5 hours for combined ADLs and IADLs, with at least 4 hours for ADLs
<p>ADLs=activities of daily living; IADLs= instrumental activities of daily living. ADLs include personal hygiene (bathing, toileting, shaving, and brushing teeth), eating (including food preparation), mobility (transferring in and out of bed, dressing, walking, standing, climbing stairs, and leaving and returning home). IADLs are household activities (shopping, cooking, cleaning, washing clothes, washing dishes, and heating the home). <i>Source:</i> German Sozialgesetzbuch XI paragraph §15.</p>			

Table 2: Long-Term Care Insurance Beneficiaries, by Level (in '000s and by percent) *

	Home and Community-Based Care				Institutional Care				Total			
	1996		2001		1996		2001		1996		2001	
	#	%	#	%	#	%	#	%	#	%	#	%
Level I: Substantial	508	(43.8)	668	(55.3)	112	(29.10)	219	(37.9)	620	(40.0)	887	(49.0)
Level II: Severe	507	(43.7)	437	(34.6)	163	(42.3)	243	(42.0)	670	(43.3)	680	(37.6)
Level III: Very Severe	146	(12.6)	127	(10.1)	110	(28.6)	116	(20.1)	256	(16.5)	243	(13.4)
Total	1,162	(100)	1,262	(100)	385	(100)	578	(100)	1,547	(100)	1,810	(100)

* Not including private insurance.

Source: German Ministry of Labor and Social Affairs. Available at: <http://www.bmgesundheit.de>, accessed December 15, 2002.

Table 3: Average Number of Beneficiaries (in thousands) and Percent Distribution, by Year *

	1995	1996**	1997	1998	1999	2000	2001
	#	#	#	#	#	#	#
	%	%	%	%	%	%	%
Community	1,068.7	1,201.2	1,263.2	1,285.5	1,349.6	1,331.7	1,353.3
	100.0	76.9	73.1	71.6	71.5	70.8	70.3
Institutions	0	360.8	464.1	509.3	538.9	550.4	571.8
	0.0	23.1	26.9	28.4	28.5	29.2	29.7
Total	1,068.7	1,562.1	1,727.4	1,794.7	1,888.5	1,882.1	1,925.1

*Not including private insurance

** Institutional benefits began July 1996

Source: German Ministry of Labor and Social Affairs. Available at: <http://www.bmgesundheit.de>, accessed December 15, 2002.

Table 4: Monthly benefits for Home Care and Institutional Care, in Euros*

Disability Level	Home Care Cash Benefit /Service Benefit	Partial day or Partial-night Institutional Care Service Benefit	Short-term Institutional Care (up to 4 weeks per year)	Supplemental Benefit for General Care Needs (annual amount)	Full-time Institutional Care Service Benefit
Level I: Substantial	205/384	384	1,432	460	1,023
Level II: Severe	410/921	921	1,432	460	1,279
Level III: Very Severe	665/1,432	1,432	1,432	460	1,432
Hardship Cases	-/1,918				1,688

*Benefits, originally expressed in deutsche marks, were converted to Euros at a rate of 1.955 DM per Euro.
Source: German Sozialgesetzbuch XI, paragraphs 37-37, 41, 42.

Table 5: Average Number of Community-dwelling Beneficiaries (in thousands) and Percent Distribution, by Benefit Type and Year*

Community Benefit	1995	1996*	1997	1998	1999	2000	2001
	# %						
Cash	887.4 83.0	943.9 78.6	971.9 76.9	962.7 74.9	982.9 72.8	954.7 71.7	962.1 71.1
Service	82.8 7.7	105.9 8.8	119.4 9.5	133.9 10.4	152.6 11.3	159.7 12.0	161.7 11.9
Combination Service/Cash	82.3 7.7	135.3 11.3	157.5 12.5	171.8 13.4	192.6 14.3	193.0 14.5	201.7 14.9
Respite Care	10.8 1.0	6.8 0.6	3.7 0.3	4.1 0.3	5.7 0.4	6.3 0.5	7.5 0.6
Partial-day or Partial-night Institutional Care	1.8 0.2	3.6 0.3	5.1 0.4	6.8 0.5	8.7 0.6	10.3 0.8	12.2 0.9
Short-term Institutional Care (up to 4 weeks per year)	3.6 0.3	5.7 0.5	5.6 0.4	6.2 0.5	7.1 0.5	7.7 0.6	8.1 0.6
Total	1068.7	1201.2	1263.2	1285.5	1349.6	1331.7	1353.3

*Not including private insurance.
Source: German Ministry of Labor and Social Affairs. Available at: <http://www.bmggesundheit.de>, accessed December 15, 2002.

Table 6: Program Income and Expenditures (in billions of Euros)*

	1995	1996	1997	1998	1999	2000	2001
Income	8.41	12.04	15.94	16.00	16.32	16.55	16.81
Expenditures							
Cash Benefit	3.04	4.44	4.32	4.28	4.24	4.18	4.11
Home-based Service Benefit	0.69	1.54	1.77	1.99	2.13	2.23	2.29
Respite Care & Retirement Contributions for Caregivers	0.44	1.06	1.24	1.22	1.20	1.17	1.09
Partial-day/-night Care & Short-term Institutional Care	0.06	0.12	0.14	0.16	0.17	0.20	0.22
Assistive Devices	0.20	0.39	0.33	0.37	0.42	0.40	0.35
Institutional Care**	-	2.69	6.41	6.84	7.18	7.48	7.75
Institutional Care for Developmentally Disabled**	-	0.01	0.13	0.22	0.20	0.21	0.21
Administrative Costs	0.55	0.60	0.78	0.80	0.79	0.80	0.82
Other		0.01	0.01	0.02	0.01	0.02	0.02
Total Expenditures	4.97	10.86	15.14	15.88	16.35	16.67	16.87
Excess of Income over Expenditures	3.44	1.18	0.80	0.13	-0.03	-0.13	-0.06
Surplus***	2.87	4.05	4.86	4.99	4.95	4.82	4.76

*Not including private insurance.

** Coverage began July 1996.

*** In the first year, 0.56 billion was set aside for investment.

Source: German Ministry of Labor and Social Affairs. Available at: <http://www.bmggesundheits.de>, accessed December 15, 2002.

Endnotes

¹ Ministry of Health. *Second Report on Developments in Long-term Care Insurance* 14/5590 (Bonn, March 15, 2001) (in German), p. 121.

² Ibid.

³ A majority of Germans are covered by the sickness funds, but individuals with income over a set threshold may purchase private health and long-term care insurance as an alternative. The private coverage has the identical benefits and eligibility criteria.

⁴ There is a maximum on the earnings subject to the tax (2345 Euros per month in 2002, approximately \$2,345), the same maximum as for health insurance.

⁵ Igl, G., et al. *Qualität in der Pflege. Betreuung und Versorgung von pflegebedürftigen alten Menschen in der stationären und ambulanten Altenhilfe* (Schattauer Verlag: Stuttgart, 2002).

⁶ German Ministry of Social Affairs. "Social Long-term Care Insurance [in German]." *Bundesarbeitsblatt* (March 1999): 127.

⁷ ADLs include personal hygiene (bathing, toileting, shaving, brushing teeth), eating (including food preparation), and mobility (transferring in and out of bed, dressing, walking, standing, climbing stairs, leaving and returning home). IADLs are household activities (shopping, cooking, cleaning, washing clothes, washing dishes, heating the home).

⁸ The medical office is allowed to designate certain individuals already at Level III to be "hardship" cases if they need at least two simultaneous caregivers at night, or if they need at least seven hours of ADL assistance per day with at least two hours occurring at night; see: German Parliament, 13. Voting Period. *First Report on Developments in the Long-term Care Insurance Program* 13/9528, (Bonn, December 19, 1997), p. 33 (in German).

⁹ A proposal to add a flat 30 minutes to the ADL and IADL time calculated for persons with dementia was rejected on the basis that too many additional beneficiaries would qualify for the program and, therefore, it was too expensive. Available at: www.bmgesundheit.de, accessed December 23, 2002.

¹⁰ Available at: www.bmgesundheit.de 12/23/02.

¹¹ Infratest consumer survey results for 1998 reported in Schneekloth, Ulrich, and Udo Mueller. *Effects of the Long-term Care Insurance* 127 (Bonn: Ministry of Health, 1999) (in German).

¹² Ministry of Health, March 15, 2001, op. cit., pp. 86-120.

¹³ Ibid., p. 55. Eligibility is made retroactive to the date of application.

¹⁴ Results are based on a population survey conducted in 1998 by Infratest and commissioned by the German government. The response rate to the survey was 67 percent. Infratest survey results are all reported in Schneekloth and Mueller, 1999, op. cit. A very similar survey, conducted by Infratest in 1991, formed the basis for many of the eligibility and financing estimates for the program.

¹⁵ The latter presumably were seeking “hardship” status, explained in endnote 5 above.

¹⁶ Based on a local survey of 335 consumers living in the German city, Moenchengladbach, in 1999 reported in van den Wijngaart, Mary, and Claire Ramakers. *Client and Quality* (Cologne, Germany: Kuratorium Deutsche Altershilfe, 2001).

¹⁷ Wijngaart and Ramakers, 2001, op. cit.

¹⁸ Long-term Care Quality Assurance law, changing paragraph 18 of the Long-term Care Law (German Social Law Volume XI) passed September 9, 2001, and effective January 2002.

¹⁹ Schneekloth and Mueller, 1999, op. cit.

²⁰ Infratest consumer survey results for 1998 reported in Schneekloth and Mueller, 1999, op. cit., p. 80.

²¹ Wijngaart and Ramakers, 2001, op. cit.

²² Infratest consumer survey results for 1998 reported in Schneekloth and Mueller, 1999, op. cit., p. 80.

²³ A local survey finds that 17 percent of beneficiaries did not receive the cash directly, Wijngaart and Ramakers, 2001, op. cit.

²⁴ German Bundestag. *Fourth Report on the Situation of the Older Generation in the Federal Republic of Germany* 14/8822 (April 18, 2002).

²⁵ Infratest consumer survey results for 1998 reported in Schneekloth and Mueller, 1999, op. cit., p. 63.

²⁶ Wijngaart and Ramakers, 2001, op. cit.

²⁷ Ibid.

²⁸ Schunk, Michaela. “Empowerment in Pathways Through Care: A Cross-National Comparison of Care Delivery Systems in Britain and Germany.” In Leonard F. Heumann, Mary E. McCall, and Duncan P. Boldy (eds.), *Empowering Frail Elderly People* (London: Praeger, 2001), p. 233.

²⁹ Long-term Care Quality Assurance Law, September 9, 2001, op. cit.

³⁰ Ministry of Health, 2001, op. cit., p. 115.

³¹ Wijngaart and Ramakers, 2001, op. cit., p. 234.

³² Ibid., p. 131.

³³ Infratest consumer survey results for 1998 reported in Schneekloth and Mueller, 1999, op. cit., p. 75.

³⁴ German Ministry of Labor and Social Affairs. *Report of the Ministry for Labor and Social Affairs to Parliament* (Bonn: Author, March 7, 1997) (in German).

³⁵ Wagner, Alexander, and Lothar Luerken. *Long-term Care Report of the Medical Office for the Period 1999-2000* (Essen, Germany: Medical Office of the Association of Sickness Funds, 2001). Currently, a disproportionate share of beneficiaries are widows living alone, a consequence of World War II. Over time, officials estimate that fewer people will choose the service or institutional benefits, despite an overall aging of the population, because more beneficiaries will have a spouse living at home.

³⁶ German Ministry for Labor and Social Affairs. *First Report of the Ministry for Labor and Social Affairs to Parliament in Accordance with S. 10 subpara. 4 Sozialgesetzbuch XI* (Bonn: Author, September 12, 1997); Ministry of Health, 2001, op. cit., p. 181.

³⁷ Infratest consumer survey results for 1998 reported in Schneekloth and Mueller, 1999, op. cit.

³⁸ Infratest national representative survey of providers for 1998 reported in Schneekloth and Mueller, 1999, op. cit.

³⁹ Federal grant funds subsidized the creation of 200 placements for persons with particular conditions, such as multiple sclerosis, quadriplegia, or Alzheimer's disease, but these were primarily institutional arrangements with unique architectural features; Ministry of Health, 2001, op. cit., p. 92.

⁴⁰ Ministry of Health, 2001, op. cit., p. 93.

⁴¹ Infratest consumer survey results for 1998 reported in Schneekloth and Mueller, 1999, op. cit.

⁴² Ibid.

⁴³ In 1998 the benefits were expressed in deutsche marks. Cash benefits for Level I, II, and III were DM 400, DM 800, and DM 1300, while service benefits were DM 750, DM 1,800 and DM 2,800.

⁴⁴ Infratest consumer surveys for 1991 and 1998 reported in Schneekloth and Mueller, 1999, op. cit., p. 52.

⁴⁵ Ibid.

⁴⁶ Schunk, Michaela, and Carroll L. Estes. "Is German Long-term Care Insurance a Model for the United States?" *International Journal of Health Services* 31 (3) (2001): 617–34.

⁴⁷ Available at: www.bmgesundheit.de, accessed December 20, 2002.

⁴⁸ In 2002 the monthly reference salary was 2,345 Euros in the former West Germany (1,960 Euros in the former East Germany).

⁴⁹ Infratest consumer survey results for 1998 reported in Schneekloth and Mueller, 1999, op. cit., p. 55.

⁵⁰ Infratest consumer survey results for 1991 and 1998 reported in Schneekloth and Mueller, 1999, op. cit., p. 52.

⁵¹ Infratest consumer survey results for 1998 reported in Schneekloth and Mueller, 1999, op. cit., p. 71.

⁵² *Ibid.*, p. 51.

⁵³ Wijngaart and Ramakers, 2001, op. cit., p. 234.

⁵⁴ Infratest provider survey results for 1998 reported in Schneekloth and Mueller, 1999, op. cit.

⁵⁵ Annual Mikrozensus data reported in Ministry of Health, March 15, 2001, op. cit., p. 89.

⁵⁶ Infratest provider survey results for 1998 reported in Schneekloth and Mueller, 1999, op. cit.

⁵⁷ German Bundestag, April 18, 2002, op. cit.

⁵⁸ Although the law was passed in 2000, its implementation was delayed when two Laender blocked the implementing regulations, citing Laender rights over federal rights in matters of education and training programs. However, in late 2002 the German high court ruled in the federal government's favor, and most provisions will be implemented mid-2003 (Law Regarding Practitioners of Elder Care [Elder Care Law], November 17, 2000).

⁵⁹ Ministry of Health, 2001, op. cit., p. 74.

⁶⁰ *Ibid.*, p. 69

⁶¹ German Ministry of Social Affairs. "Social Long-term Care Insurance (Germany)." *Bundesarbeitsblatt* (March 1999): 127 (in German).

⁶² Ministry of Health, 2001, op. cit., p. 24.

⁶³ *Ibid.*, p. 121.

⁶⁴ For example, articles in news magazines, such as “Exit via Neglect.” *Der Spiegel* (February 1999).

⁶⁵ Bundeskonferenz fuer Qualitaetssicherung im Gesundheits-und Pflegewesen. Press release, January 14, 2000. Available at: www.buko-qs.de.

⁶⁶ Knaepple, Annerose, Stefanie Bohns, and Christine Rauscher. *Model Program of the Sickness Funds, Improving the Quality of Long-term Care* (Bad Duerrheim, Germany: VDAK, n.d.).

⁶⁷ Results from a regional telephone survey conducted by the VDAK sickness fund association in 1999 and reported in Ministry of Health, 2001, op. cit., p. 125.

⁶⁸ Infratest consumer survey results for 1998 reported in Schneekloth and Mueller, 1999, op. cit., p. 70.

⁶⁹ Wijngaart and Ramakers, 2001, op. cit.

⁷⁰ German Bundestag, April 18, 2002, op. cit.

⁷¹ J. Wilbers *Long-term Care in Germany*. Mimeo (Trier, Germany: Author, 1998) (in German).

⁷² Ministry of Health, 2001, op. cit., p. 98.

⁷³ Schneekloth and Mueller, 1999, op. cit., p. 57.

⁷⁴ Ministry of Health, 2001, op. cit., p. 20.

⁷⁵ Bundeskonferenz, January 14, 2000, op. cit.

⁷⁶ Ibid.