ABSTRACT: Self-directed care is an alternative way of delivering services that seeks to empower participants by expanding their degree of choice and control in selecting services. Over the last decade, it has been widely adopted internationally in home and community-based long-term care for people with physical and cognitive disabilities and for seniors. It has been shown to improve satisfaction with services, improve quality of life, and reduce costs compared with services from an agency. A small number of pilot programs are now experimenting with self-directed care in other areas; for example in the management of serious mental illness and other chronic conditions. If positive findings from long-term care can be replicated, self-directed care can make an important contribution to improving health care quality and effectiveness. This issue brief examines a range of innovative self-directed care programs in England, Germany, the Netherlands, and the United States.

Introduction

In the mid-1990s, Medicaid introduced a self-directed care demonstration program, known as “Cash and Counseling.” Cash and Counseling sought to expand options for home and community-based long term care services. The targeted audience included seniors and children and adults with disabilities who were eligible for Medicaid personal care or home and community-based waiver services. Specifically, the program allowed beneficiaries to manage their own budgets and choose services that met their care needs. Based on positive findings from the demonstration, Cash and Counseling and other, similar types of self-directed personal care programs now operate throughout the United States.²

The development of self-directed care in the United States has been mirrored by developments in European long-term care. In addition, in recent years, there has
been increased interest in extending self-directed care into other health services areas as a way of increasing patient-centered care. This issue brief will define self-directed care (SDC), discuss the development of SDC internationally, show the impact of SDC on long-term care, and discuss early efforts to extend SDC into health care internationally. The brief focuses on developments in England, Germany, the Netherlands, and the United States.

Self-Directed Care in Long-Term Care

Self-directed care is based on the premise that giving individuals control of a budget with which to purchase services allows them to tailor care to meet their specific needs. In doing so, it can empower participants and their families by expanding their degree of choice and control over services. SDC uses a variety of names internationally. In the United States, two of the large SDC initiatives developed under Medicaid are Cash and Counseling and Independence Plus. In England, the program is referred to as direct payments or individual budgets. In the Netherlands and Germany, it is called personal budget. Germany also uses the term cash payments for care. Appendix A provides details of the programs in different countries.

In the countries examined in this issue brief, self-directed care is offered as an option to individuals who are eligible to receive publicly funded long-term care services. Eligibility for adults is based on a combination of severity of functional impairment and level of income and assets. Children's eligibility may be determined by severity alone without taking family income into consideration, as in the Netherlands and under the Katie Beckett waiver in Medicaid.

Countries pursuing SDC have tended to adopt one of two models. In countries such as Germany and Austria, a cash payment for care is provided to those eligible for long-term care services with few strings attached—the “open” model. The cash allowance can be spent however the recipient chooses and the money does not have to be accounted for. The only restriction is that individuals receiving the allowance and their relatives must ensure that adequate care is obtained. The well-being of the care recipient is reviewed every three to six months. If care is deemed insufficient, the cash allowance is withdrawn in favor of services provided by a home care agency. In practice, the majority of the cash allowance goes to pay informal caregivers.

The other model, which might be termed the budgeted or planned model, was adopted initially in England, the Netherlands, and the United States, and maintains a more direct connection between a participant's needs and the goods and services purchased to meet those needs. In recent years, approaches to SDC internationally have started to converge. In 2004, Germany launched a personal budgets demonstration based on the planned model and a gradual shift from cash payments to personal budgets has now been formalized in legislation. This second model tends to follow a three-step process.

First, an individual budget is calculated for an eligible person, indicating how much is available to spend in a year on home and community-based long-term care services. The individual budget does not include the costs of institutional care if the recipient can no longer remain at home nor does it include the costs of medical care. An individual budget may be set in one of three ways: 1) it may be based on the cost of services that would otherwise be authorized for an individual if he or she chose services delivered by a home care agency, 2) it may be based on the cost of services used by an individual in the previous year, or 3) it may be based on a predictive model that matches an individual’s needs to a budget amount. Regardless of approach, the individual budget is funded exclusively from public resources and does not include private savings.

Step two is a planning phase. Consumers identify their needs and goals for care through a person-centered planning process. This forms the basis for developing an annual spending plan, which must fit within the overall individual budget allocation. Items listed in the spending plan must relate to the goals and needs identified in the care plan. For example, if weight loss is an identified goal, the consumer may choose to use funds from his or her budget to purchase a gym membership or join Weight Watchers. In step three, the spending plan must
be approved by the government agency running the program or a designated agent.

Individuals must account for purchases against their approved spending plan by regularly submitting a record of purchases and receipts to the program agency. Individual budget funds are transferred to program participants on a monthly or quarterly basis as a safeguard against individuals spending their entire annual budget at once. All programs prohibit using funds for certain purchases, such as alcohol, illegal drugs, and debt repayment, and most require money spent on nonapproved purchases to be repaid. To improve financial control and make the accounting process simpler, programs in the United States use third-party financial management organizations to control payments. Once an individual has completed a spending plan, payments are made directly by the financial management organization and requests for payment are only fulfilled if they accord with an approved spending plan. A small number of programs in the United States and United Kingdom have developed preloaded debit cards that use smart-card technology to permit only authorized purchases and transmit information about purchases made directly to program managers.

It is common for programs to also provide participants with a counseling service to advise them how to use their individual budget, about the types of choices available, and how to plan for emergencies. In the United States, this is a formal part of SDC and is funded directly by government agencies. In other countries, participants can purchase the services of independent counselors but often rely on peers and other informal networks for advice. Research in England has demonstrated that the failure to provide all SDC participants with a counseling service has acted as a barrier to the take-up of SDC, particularly among the most vulnerable groups, such as those with serious mental illnesses.

**The Impact of Self-Directed Care**

Despite significant differences in programs across countries, evaluations reveal a consistently positive picture. The following section discusses the impact of SDC in long-term care in the following areas: personalization of services, access to and coordination of services, consumer satisfaction, service utilization and health outcomes, and costs.

**Personalization**

Program evaluations indicate that by having the flexibility of an individual budget, consumers make use of a greater diversity of goods and services than would be otherwise available. For example, in the New Jersey Medicaid Cash and Counseling demonstration, the 556 beneficiaries who opted to direct their own services purchased items from 25 different categories, including transportation, durable medical equipment, house cleaning, and alternative therapies. The usual Medicaid State Plan personal care benefit offers only a few additional types of support alongside hands-on assistance.

An evaluation of England’s individual budget pilot program found a similar diversity of purchases. The program includes 13 sites covering seniors and adults with physical, cognitive, and psychiatric disabilities who are eligible for long-term care and other disability support services. Service utilization information is available for 169 participants in the pilot program. All these participants continued to purchase traditional services such as home care and meal services, but 59 percent also made nontraditional purchases, including education courses, computer equipment, restaurant meals, child care, and gym memberships. Overall, this diversity reflects the fact that SDC allows consumers to meet specific individual needs and preferences to remain independent and in their own homes. These services would not necessarily be covered by a traditional personal care or home and community-based services benefit.

**Access to and coordination of services**

Self-directed care has been shown to improve access to home and community-based services by overcoming capacity constraints in traditional delivery systems. For example, in the first year of the Cash and Counseling demonstration in Arkansas, consumers in the experimental group who chose to direct their own services obtained 100 percent of the paid hours of personal care compared with the control group who received only 70 percent of their authorized hours. Individuals in the experimental
group were able to hire family members, friends, and neighbors to provide care. Alternatively, control group participants were reliant on traditional home care agencies that provide services under the Arkansas Medicaid State Plan personal care benefit. These agencies did not have sufficient staff to provide all consumers with their full entitlement. Similarly, the fastest-growing user group of personal budgets in the Netherlands is families with children with attention-deficit hyperactivity disorder, autism, and other types of serious emotional disturbances. These families gravitated toward personal budgets, in part, because of a shortage of appropriate services in the traditional long-term care system.

In England, research showed that of 44 recipients of direct payments with complex, high-level support needs, more than three-quarters were using their direct payment to pay their personal assistants to perform health-related tasks. Doing so improved the flexibility and coordination of their care by integrating health and personal care needs. Users in the study wanted direct payments to be formally extended to acknowledge and legitimate the help they were already receiving and to enable them to receive more. A similar finding was reported in the Florida Cash and Counseling evaluation, particularly by parents of children with mental retardation and developmental disabilities.

Satisfaction with services
One of the strongest findings about self-directed care is increased satisfaction among service users. An evaluation of the personal budgets program in the Netherlands found that close to 80 percent of disabled and elderly participants who were eligible for long-term care services and opted for a personal budget had a positive assessment of the services they received compared with less than 40 percent among those receiving directly provided services. A survey of 562 direct payment users in England who employ a personal assistant revealed that 79 percent were very satisfied with the care and support they received. Of those who had previously received services provided directly by a local government agency, only 26 percent had been very satisfied.

The same study also found that workers who are directly employed by service users tend to be satisfied with their jobs. Ninety-five percent of personal assistants were happy with their roles and 90 percent felt appreciated either most of the time or frequently.17

Quality of life and health outcomes
There is no evidence that health or other quality-of-life outcomes deteriorate under individual control. This holds true for older participants and those with mental health conditions. Mentally ill adults with physical disabilities in the New Jersey Cash and Counseling program were less likely to fall, have respiratory infections, develop bed sores, or spend a night in hospital or a nursing home if they were directing their own personal care services than if they were receiving agency services. Even programs with limited oversight, such as in Germany, have not found significant cases of neglect.

Costs
For the most part, individuals are good stewards of public money. Frequently, budgeted funds are unspent, indicating that individuals do not necessarily exhaust their allocations and purchase more goods and services than they need. In the Netherlands, for example, 17 percent of total funds allocated to individual budgets went unspent in 2005. Programs report few, if any, cases of fraud and abuse. It is worth noting, however, that many programs are relatively small, and these issues could become more prevalent once programs are taken to scale.

In England, long-term care services purchased directly by individuals have been shown to cost between 20 percent and 40 percent less than the equivalent services provided by local government. The Cash and Counseling demonstration in Arkansas resulted in an increase in spending on Medicaid personal care in the experimental group because participants received their full personal care entitlement, unlike control group participants. However, increased spending on personal care kept more people out of nursing homes, resulting in an 18 percent reduction in nursing home use over a three-year follow-up period and in overall Medicaid savings.
From Long-Term Care to Chronic Care

Several countries are taking initial moves to extend self-directed care as an option for patients with chronic conditions. Discussions of individual budgets are still in preliminary stages, but there have been no suggestions that individual budgets should cover a patient’s entire annual health care spending. The focus is condition-specific and targeted at aspects of care and disease management where patients’ experience and expertise can make a difference to outcomes. For instance, a patient with diabetes who needs to stop smoking and lose weight could be given a small individual budget in place of hospital-based smoking cessation and nutrition services. Funds from this budget could be used to meet the same goals in community-based settings and through alternative programs. Positive evidence from long-term care suggests several potential benefits from such an extension. First, SDC offers the potential for people to obtain services more tailored to individual preferences and needs. This is particularly important in the context of chronic disease where self-management and individual behavior change are integral to effective disease management. Second, consumers directing their own long-term care services have been shown to be better able to coordinate their care than those receiving agency services. The extension of SDC into chronic care may improve overall care coordination for consumers who also need long-term care services and can receive an individual budget that integrates their personal care and home health needs. This kind of integrated budget could allow an individual to train a personal attendant under delegated nurse supervision to perform routine health care tasks such as catheter or wound care, integrating these into his or her daily personal care routine. Finally, SDC has the potential to increase the value of health care dollars by improving the effectiveness of care without increasing its costs or by reducing the overall costs of care.

Extending SDC into health care is not without risks. The most significant risk is that states will use individual budgets to cap spending on health care and transfer a greater proportion of risk for unexpected health care needs to individuals. For example, long-term care programs in Germany and the Netherlands provide individual budgets that are significantly smaller than the cost of in-kind services: 50 percent lower in Germany and 30 percent lower in the Netherlands. If this approach were adopted in health care it could be harmful to patients, leaving them unable to access needed care. No such risks have been observed to date because SDC is not widespread enough to serve as an effective cost control measure. The integrity of SDC depends on states and health plans being prohibited from penalizing individuals who choose SDC, either by giving them budgets that are significantly lower than the cost of in-kind services or by including the costs of inpatient and emergency care in individual budgets. Including these benefit categories can lead to patients exhausting their budgets and being unable to access care.

The largest SDC initiative outside of long-term care is the United Kingdom’s pilot of personal health budgets in the National Health Service (NHS) in England. In a small number of cases, the NHS is already contributing to self-directed budgets for people with complex long-term health conditions that result in significant functional impairment; for example, muscular dystrophy, severe epilepsy, and chronic obstructive pulmonary disease. In most cases, self-directed care has enabled these patients to avoid long-term residential placement or hospitalization and, on a case-by-case basis, has saved the NHS considerable resources. As part of the pilot, 20 of 80 regional health bodies, or primary care trusts (PCTs), in England have been selected as pilot sites that will be part of an in-depth evaluation. Other PCTs can choose to participate but will not be part of the formal evaluation. Pilots will include mental health, long-term chronic conditions, maternity care, substance abuse, children with complex health conditions, and end-of-life care. Because this is an experimental program, the rules are limited to broad principles: no one will be denied essential treatment as a result of having a personal health budget and there must be clear accountability for the choices made with a personal health budget. The government is encouraging pilot sites to test different ways of using and managing individual budgets; for example, have the budget held by a third party organization or by a professional rather than directly by an individual.
Legislation has been passed that gives PCTs the authority to pay money directly to individuals if they choose. Regulations will be published in 2010 to implement this new legal authority.

Health insurance reform in the Netherlands includes a small provision for self-directed care. Individuals are permitted to have a personal budget within their health insurance plan, limited to a few specific conditions and benefit categories, such as outpatient mental health services. Individuals with mental health conditions can choose a personal budget and make choices about the treatment they follow, but the use of unlicensed and alternative providers is prohibited.

A few states in the United States, including Florida and Texas, have implemented SDC programs for adults with serious mental illnesses. These programs target adults with mental health disorders classified as Axis I or Axis II under the Diagnostic and Statistical Manual of Mental Disorders; for example schizophrenia or bipolar disorder. Individuals have access to budgets of approximately $4,000 in Florida and $7,000 in Texas. In Florida, the budget is based on the average spent per individual across Medicaid and on state general revenue funds in the two parts of the state where the SDC program is available. The approach was designed to create a budget-neutral program but budgets have not been recalculated since the program began in 2001. In Texas, the budget is based on the value of the complete package of Medicaid outpatient mental health and rehabilitative services that an individual with an Axis I or II diagnosis is entitled to receive. These budgets cover outpatient mental health and rehabilitation services only. Inpatient care, emergency care, pharmacy, medical care, and substance use services are not included within the individual budget. The Florida program requires individuals to spend 48 percent of their budget on Medicaid state plan mental health services and the Texas program requires 60 percent to be spent on treatment as a safeguard against individuals choosing only alternative services. In Texas, the 60 percent can include treatment services not covered in the Medicaid state plan.

As SDC in mental health develops, individual budgets are evolving from supplementary funds to an alternative to Medicaid state plan mental health services. To reflect this, budgeting is shifting away from a single budget amount for all participants to a banded approach based on severity and previous Medicaid spending. But individual budget methodologies currently lack the sophistication some states have achieved in home and community-based long-term SDC.

Program participants can use their individual budgets to purchase traditional services, such as therapy or case management; alternative therapies; and other support services to improve their mental health and ability to function in the community. Participants who purchase traditional services can choose to go outside the Medicaid provider network. These programs combine funding from public insurance programs with state revenue to give consumers greater flexibility over the kinds of goods and services they can use, some of which would not be eligible for reimbursement under Medicaid or Medicare.

From the perspective of participants, early evidence from these mental health programs is promising and reinforces findings around personalization and consumer satisfaction in long-term SDC. The programs offer individuals an opportunity to craft a highly personalized package of services to support their mental health recovery, a process that is itself highly individualized. This is not only important with regard to nontraditional, rehabilitation, and support services, such as peer support or job coaching, but in improving access to traditional services. Given the restrictions placed on behavioral health services and medications under some Medicaid state plans, SDC gives participants access to a wider range of clinical service providers by not limiting them to those who accept Medicaid. In Texas, for example, Medicaid will not cover routine counseling, despite clinical guidelines to the contrary. SDC is providing individuals access to counseling using funds from their individual budgets.

There is also positive early evidence regarding service utilization and outcomes. Exhibit 1 compares services purchased with an individual budget and those provided through the Medicaid program. Participants in self-directed care make significantly less use of crisis stabilization and crisis support compared with nonparticipants and greater use of routine care and supported...
This positive shift toward prevention and early intervention is associated with improved outcomes, including more days in the community than in inpatient settings, higher scores on the Global Assessment of Functioning Scale (a numeric scale used by mental health clinicians and physicians to rate the social, occupational, and psychological functioning of adults), and a greater percentage of participants in paid employment and training.

These outcomes are also positive from the state’s perspective because crisis services are the most costly—inpatient crisis services cost $500 to $650 per day. As yet, there has been no move to use SDC to cap spending by reducing budgets year on year to reflect savings. Fewer than 600 individuals participate in SDC in Florida and Texas, out of a total population of people with serious mental illnesses of many thousands. These programs represent too small a fraction of state Medicaid spending on behavioral health to represent effective cost control.

Exhibit 1. SDC Participants Use More Preventive Care, Fewer Crisis Support Services


Lessons for U.S. Health Policy

Positive evidence from several countries about self-directed long-term care has created momentum toward extending the approach into chronic care, where initial evidence is also encouraging. As policymakers consider the extent to which SDC might be more widely relevant to health care in the United States, it is interesting to consider which types of payment system may best support SDC. SDC began in Medicaid fee-for-service, facilitated by Medicaid waivers. However, more recently, it has been integrated within Medicaid managed care both in long-term care and in mental health and has been introduced into the Veterans Administration (VA) to provide improved access to home and community-based services to veterans who are at risk of being placed in nursing homes. In 2008, the VA introduced a self-directed home and community-based services program in partnership with the Administration on Aging to help veterans of all ages who are not Medicaid-eligible and are at risk of nursing home placement to remain in their homes. The program is currently operating in 20 states. These recent developments suggest that SDC can be compatible with different payment systems, including capitated private sector health plans.

There are questions regarding which populations are best suited to SDC. The fact that SDC has been successful with vulnerable groups, such as low-income seniors and people with physical and psychiatric disabilities, may indicate that SDC could be made broadly available in health care. However, there may be other important reasons for considering targeting more specific populations. For example, a pilot program that began in 2009 for adults with serious mental illnesses in Medicaid managed care in Delaware County, Pennsylvania, is targeting individuals who have received Medicaid mental health services in eight consecutive quarters over a two-year period, have not had an inpatient episode in the last six months, and have had fewer than five inpatient episodes in the last 24 months. This segment of the population is more likely to benefit from an individual budget that can help them move toward improved mental functioning and greater community integration. The population also has high enough costs for there to be room to
make changes in how money is spent. Individuals who receive a very small number of mental health services—for instance, only psychiatrist visits for medication management—have little room to make changes in their service package.

Questions relating to payers, target populations, and the impact of SDC in health care all require further research. New insights will emerge from the United Kingdom’s personal health budgets pilot, from the ongoing development of SDC in mental health in the United States, and from health insurance reform in the Netherlands. Evidence from these developments will indicate whether giving patients choices and control over their services and treatments—beyond simply choice of provider—can improve the quality and outcomes of health care while reducing costs.

Notes

1 Support for Cash and Counseling was provided by the Robert Wood Johnson Foundation and the Office of the Assistant Secretary for Planning and Evaluation at the U.S. Department of Health and Human Services.


3 Since devolution in the United Kingdom, there have been variations in health and long-term care policies in the different countries. Therefore, this brief only deals with England.

4 For earlier information about the programs in these four countries, see J. Tilly, J. M. Wiener, and A. E. Cuellar, Consumer-Directed Home- and Community-Based Services Program in Five Countries: Policy Issues for Older People and Government (Washington, D.C.: Urban Institute, 2000).

5 The Katie Beckett waiver allows severely disabled children to qualify for Medicaid home and community-based services on the basis of their income alone and not that of their parents.


9 M. Meiners, D. Loughlin, M. Sadler and K. Mahoney, Clarifying the Definition of Personal Care: Findings on the Purchase of Equipment, Goods, and Services under the Cash and Counseling Demonstration and Evaluation in Arkansas and New Jersey (Chestnut Hill, Mass.: University of Maryland Center on Aging and Boston College, 2005).


12 Personal communication with Dutch Health Care Council, an independent advisory body to parliament and the government.


17 Ibid.


21 Personal communication with Dutch Health Care Council, an independent advisory body to parliament and the government.


23 Benjamin and Fennell, “Putting Consumers First in Long-Term Care,” 2007.


## Appendix A. Summary of Self-Directed Care Programs In Four Countries

<table>
<thead>
<tr>
<th>Country</th>
<th>Program development</th>
<th>Program features</th>
<th>SDC vs. traditional services: number of participants and overall spending</th>
<th>Average size of individual budget</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Compulsory accounting of purchases?</td>
<td>Universal support services provided?</td>
<td>Employing immediate family permitted?</td>
</tr>
<tr>
<td>Germany</td>
<td>Cash payments for care (Pflegegeld) introduced in 1995. Personal budgets demonstration program (Persoenliches Budget) began in 2004. Intention to shift from cash payment to personal budgets included in 2008 legislation.</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Netherlands</td>
<td>Personal budgets (Persoonsgebonden Budget) introduced in 1996. A relaxation of accounting requirements in early 2000s led to dramatic growth in overall costs. Accounting procedures reintroduced.</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>United States</td>
<td>Self-directed care possible under several Medicaid waivers and state plan options: 1915 (c) waivers, 1915(i) and 1915(j) state plan amendments and through state plan personal care services.</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>
About the Author

Vidhya Alakeson, M.Sc. is a policy analyst in the Office of the Assistant Secretary for Planning and Evaluation at the U.S. Department of Health and Human Services. She was a 2006–07 U.K. Harkness Fellow in Health Care Policy and previously worked in the United Kingdom for the government as well as several think tanks. She has conducted extensive research on self-directed care and its application to health care and published widely on this subject in the United States and United Kingdom. This issue brief represents the views of the author and not of the U.S. Department of Health and Human Services. She graduated with a first class degree from Oxford University in 1994 and a M.Sc. with distinction in European studies from the London School of Economics and Political Science in 1999.

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