

Consumer-directed services: lessons and implications for integrated systems of care

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Abstract

Over the past decade, policy makers in developed countries have begun to pay increasing attention to reform of the long-term care system for the frail elderly and younger people with disabilities. A continuum of strategies have generated interest, including integrated systems of care with agency/professionally managed service packages on the one end, and programs offering cash benefits along with the flexibility to decide how to best use these funds to meet individual needs and preferences, on the other. The latter approach, known as “consumer-directed care,” is found in various forms and degrees in Europe and North America. Primarily organised around the provision of home and community care, consumer-directed services are aimed at empowering clients and family carers, giving them major control over the what, who and when of needed care. Consumer-directed care appears to be the antithesis of integrated care. However, it actually holds important lessons and implications for the latter. This policy paper explores the rationale and models of consumer-directed services at home, reviews developments, designs and outcomes of programs in the Austria, Germany, the Netherlands, and the US. It also discusses how this experience could be helpful in shaping better and more responsive integrated models of care for vulnerable long term care populations.

Keywords

consumer-directed care, home and community services, long term care, integrated care

Introduction

Dramatic demographic and epidemiological changes over the past few decades have transformed the world's health care needs, making long-term care for the frail elderly and younger people with chronic and disabling conditions, a major policy issue—particularly in developed countries [1]. The sheer size of this population, coupled with its growing needs, has prompted the expansion of publicly funded home and community-based services. Nonetheless, persistent cost-effectiveness and quality concerns have stimulated interest in a continuum of other long-term care solutions. The rubric of reform includes integrated models of care with agency/professionally managed service packages, often with pooled financing, on one end, and consumer-directed approaches that give recipients of home and community services more power over arranging and directing their own care, on the other.

Consumer-directed home care programs are found in various forms in Europe and North America, even in

countries where more integrated approaches to service co-ordination and care management are being simultaneously studied or developed. The growing experience with consumer-directed services suggests that it is not only a valuable model in its own right. Despite appearances to the contrary, the know-how from consumer directed services could also make integrated care work better.

This article first explores the meaning, rationale and models of consumer-directed care.¹ This is followed by an analysis of developments, designs and experiences of select programs in Austria, Germany, the Netherlands, and the United States (US). The article concludes with an examination of the lessons learned from these programs and their implications for building more responsive and effective integrated care systems for the frail elderly and people with chronic disabilities.

¹ The philosophy inherent in “consumer direction” or “consumer-directed care” may be known by different populations (e.g. working-age adults with physical disabilities, persons with developmental disabilities, and persons with severe and persistent mental illness) as the “independent living model,” “self-determination” or “empowerment,” to name the most frequently used appellations.

Consumer-directed home and community services: rationale and models

People with disabilities depend largely on the help of others to function in their daily lives. While families represent a major source of support, an increasing amount of help with activities of daily living (ADL) such as bathing, dressing and eating, and instrumental activities of daily living (IADL) such as cooking, shopping and housekeeping is provided by workers from publicly funded home care agencies. Although mounting reliance on “formal” or agency-provided services has enabled growing numbers of disabled persons (the majority of which are the frail elderly) to remain at home, these individuals often lose control over their own lives in a case-managed system where virtually all decisions over the *what*, *who*, and *when* of home and community care become the responsibility of professional and paraprofessional workers [2].

The consumer-directed philosophy and approach are designed to maximise the autonomy and independence of persons with physical dependencies by giving them greater choice and control over personal care and other in-home services and providers [3]. Depending on the model, consumers can be empowered to assume responsibility for key decisions, including assessment of their own needs, determination of how and by whom needed services should be delivered, and monitoring the quality of services received [4]. By emphasising privacy, autonomy and the right to “manage one’s own risk,” consumer-direction is seen as a way of levelling the playing field between institutional and home- and community-based care [5].

The ideas behind consumer-directed care—allowing people to have control and autonomy over their own lives, and respecting the personal choices they make—are not new. They reflect basic humanistic values found in most cultures, and also form the ethical basis for the “helping professions” such as medicine, nursing and social work [6]. Be that as it may, consumer-directed care is also a reaction to the increasingly managerial culture of health and social care, wherein services are delivered according to the dictates of bureaucrats and professionals and consumer views are given short shrift or rarely addressed.

Critics of the traditional “agency model,” at least in the US, argue that the long-term care system, whether institutionally- or community-based, provides little opportunity for persons with physical disabilities to shape and direct their own care [7], despite the fact that most supportive services delivered at home are

low-tech, non-medical and do not require extensive training or oversight [8]. Furthermore, there is criticism that home care agencies make consumers take a ‘backseat’ to their own interests. Consequently, all manner of decisions affecting client access, satisfaction and quality of care—major tasks such as service planning, worker tasking, assignment, and scheduling, and ongoing monitoring of performance—are taken with little, if any regard for the preferences of recipients or are otherwise predisposed by an unyielding regulatory system [9].

The roots of the consumer-directed approach are found in the decades-old advocacy movements among working-age people with disabilities in the US and Western Europe [10]. These consumer movements have not only been successful in demanding the de-medicalisation and de-institutionalisation of services, but also in the development of options fostering greater self-determination, more freedom of choice and less professional and state involvement in the daily lives of people with disabilities [5, 10]. Similar views, at least in the American context, are slowly but surely taking hold among the elderly [11]. Several additional forces appear to have stimulated or bolstered interest in this new strategy. First, government is more receptive to consumer-directed care, because it promises the reduction or elimination of costly home care agencies and care managers [7]. Second, concern about the shortage of front-line home care personnel has opened policymakers to the possibility that the strategy might help with recruitment of new workers by its tapping into the “grey” market (e.g. family, friends and neighbours). Third, the growing importance of chronic illness management in the overall health system is driving more “activated patients” to play a more central role in their own care, thus potentially enhancing the importance of consumer-directed services at home [12].

Despite the positive rationale, consumer-directed care raises several concerns. Doty, Benjamin, Matthias and Franke [13] suggest that agency-managed services may produce better outcomes because of the importance that professional supervision plays in quality care. Client capacity for independent decision-making, liability related to poor service outcomes (e.g. health status and quality of care), and accountability for the use of public funds are also frequently mentioned issues [14, 15].

Benjamin [8], Egley [16], and Tilly and Wiener [17] point out that consumer-directed care is not a single approach, but constitutes an array of models differing in terms of the level and type of decision-making, autonomy and control vested in the client vs. the home care agency and/or public long-term care sys-

tem. Moreover, programs vary in key areas such as functional and financial eligibility, covered services, benefit limits, hiring restrictions (e.g. family members), administrative structure, and funding source (i.e. social insurance or general revenues) [14]. Roughly speaking, three major approaches can be discerned:

- *Professionally monitored model.* Clients are able to hire and fire workers of their choice. However, recipients receive mandated guidance from care managers, who are also responsible for monitoring services over time according to an approved care plan.
- *Professionally assisted model.* Care managers initially determine program eligibility and approve service hours, but decisions regarding hiring, scheduling, supervision and termination of workers are left to the client. Professional help with key tasks may also be provided in some programs.
- *Cash model.* Clients receive periodic cash allotments and are given total discretion with respect to purchasing virtually any services or goods they deem essential. Optional professional counselling may be made available.

Several options are available to pay workers in the professionally monitored and professionally assisted models. In addition to direct payment by the public authority or the use of so-called “vouchers” to obtain services, clients may also be given the choice of managing cash on their own, or opting to have a certified fiscal agent to perform this function. Furthermore, the professionally assisted and cash models may incorporate various counselling services to help the client assess personal preferences and the ability to self-direct, as well as to identify, screen and train prospective workers.

Consumer-directed care in four countries: programs and experiences

As indicated earlier, consumer-directed programs for the elderly and people with disabilities, including payments for Informal caring, are growing in importance in developed nations [18–21]. The following is a brief review of the programs and experiences in four countries, three in Europe (Austria, Germany and the Netherlands) and one in North America (US).

Austria

Austria has been long committed to state payments for informal care [22]. Austria’s “Federal Long Term Care Allowance Act” was implemented in 1994. The

resulting social insurance-based system is administered by the regional health insurance funds. The program, which provides non-means tested cash benefits to eligible clients and replaces previously existing provincial attendance allowances, is designed to help recipients pay for care expenses, enable them to remain at home, and promote self-determination and family support [23].

Recipients must be at least three years old, permanently in need of personal assistance, and require 50 hours of care or more on a monthly basis [24]. In the case of cognitively impaired individuals, someone must be appointed to manage the allowance [22]. In 1994, there were seven benefit levels ranging from monthly cash payments of US\$ 250 to US\$ 2,000 [20].

Badelt et al. examined the initial experience of Austrian program participants [25]. The results of their mail survey, which included 3120 respondents approximately 75% of whom were age 65 and over, is summarised by Tilly and Bectel [20]. Eighty-one percent of the survey respondents reported using their care allowance to compensate family members, and nearly a third used the cash they received to perform home modifications. More than 70% of these individuals indicated that the care allowance better equipped them than previously to deal with the pressures of daily living, and 65% reported greater freedom in selecting carers.

Germany

Before 1994, Germany’s system of state support for long-term care was institutionally-biased, means-tested and administered at the provincial level by the states (Länder) [26, 27]. Three main issues led to the enactment of legislation in that year creating a universal social insurance program for long-term care: (1) the then increasing fiscal pressures on the states; (2) a growing sense that the German notion of “social solidarity” was being compromised by the old means-tested system; and, 3) the belief that the supply and quality of services were being eroded [28,29].

Germany’s program, which is similar to the Austrian entitlement and known as Social Dependency Insurance (In German, *Soziale Pflegeversicherung*), is funded through a mandatory, income-related payroll tax. The system, which gives priority to care at home over that in a nursing home, became operational between April 1995 (for home care) and July 1996 (for institutional care). Beneficiaries can receive needed in-home care in the form of in-kind services, cash, or a combination of both [30]. Responsibility for admini-

nistering this non-means tested coverage is incorporated into a separate part of the existing sickness fund structure [31]. Benefits are made available to persons regardless of age who meet the minimum functional eligibility criteria (i.e. need for assistance with at least 2 ADLs and some IADLs) [28]. There are three payment levels. The amount of cash received depends on the recipient's level of severity, and ultimately represents about 50% of the value of comparable in-kind services. Although the beneficiary is free to use funds for any services desired, Cuellar and Wiener [30] find that there are no mechanisms available to assist them in making choices, allocating services based on need, or providing information and referral to supportive services.

Runde et al. [32] examined the early experience of program participants, which included 10,400 respondents to a mail survey, three-quarters of whom were age 65 and over. Tilly and Bectel's excellent summary of this research, reports that 71% of the respondents believed the program helped to preserve their independence; 85% of the cash assistance recipients and 61% of the combination-benefit recipients participating in the survey also saw a major benefit in being able to use funds as they wished [20]. In addition, 43% of the respondents felt that the quality of their care had actually improved, with another 55% indicating that the level of quality remained about the same.

The Netherlands

A care initiative known as the Person-Centred Budget (in Dutch, *Persoonsgebondenbudget*) was introduced in 1995 by the government of the Netherlands [29]. Initially established as a demonstration, this cash assistance program was designed to promote greater choice and higher quality of care for consumers, as well as to encourage increased competition among providers [33].

Cash payments, which are financed through the country's exceptional (i.e. catastrophic) medical expense insurance program (in Dutch, *Algemene Wet Bijzondere Ziektekosten*, or AWBZ), enable eligible clients to purchase primarily ADL- and IADL-related services from the provider of their choice, including informal carers or agencies from the regulated or private markets; a small amount is set aside for flexible use [34]. Eligibility is extended to consumers of any age who need ADL and/or IADL assistance. Nursing care cannot exceed 3 hours daily [21]. Younger individuals and those with cognitive impairments must have a surrogate decision-maker to participate. Each client's monthly benefit level is determined by multiplying the hours in a professionally developed care plan by

standard, national rates; income-related deductions are then taken. An independent fiscal agent has responsibility for paying individual home care workers.

Two major studies shed important light on program outcomes. First, participants in a randomised control trial conducted by Miltenburg and colleagues during the initial demonstration phase indicated that they had more control over services than individuals in the comparison group with traditional agency-provided services [35]. Second, in a quasi-experimental study conducted several years after the Dutch program's national implementation, Woldringh and Ramakers [36] found several important participant outcomes, namely significantly more choice of, and influence and control over their services, as compared to matched controls receiving agency-provided care.

United States

More and more American states have incorporated consumer-directed features into their home care programs. Unlike the previously discussed European cash assistance programs, however, these efforts fall mainly into the professionally monitored or professionally assisted models described earlier [8, 17]. The US Department of Health and Human Services, with the support of The Robert Wood Johnson Foundation, however, is testing a cash model with a counselling component in three states (Arkansas, Florida and New Jersey [37]. Space does not permit description and discussion of the large number of consumer-directed efforts found in the US.² Suffice to say, these programs are means-tested and provide largely ADL/IADL assistance, but otherwise differ in terms of goals (e.g. client empowerment, improved care, and/or cost control), functional eligibility, benefit amounts, level of care management involvement, quality assurance, availability of worker training, and administrative responsibility. Depending on the particular program, financing comes from one or more of the following public sources: Medicaid, Older Americans Act, and State and County funds.³

There is a growing body of evidence on various aspects of the US experience with consumer-directed services. The following briefly summarises three large-scale reviews by Doty et al. [15], Tilly and Wiener

² Readers should consult two excellent reviews: Tilly, J. and Wiener, J., *Consumer-directed home and community services: Policy issues*. Washington, DC: Urban Institute, January 2001; and, Coleman, B., *Consumer-directed services for older people*, Washington, DC: AARP, November 2001.

³ Medicaid is a federal program, administered by the states, which provides health coverage to individuals who cannot afford needed care because of financial or medical indigence. The Older Americans Act is a federal program, administered on the state and local levels, which funds certain social services for older persons age 60 and over.

[17], and Tilly and Wiener [38] on the results of initiatives in several states (California, Colorado, Kansas, Maine, Michigan, Oregon, Washington and Wisconsin). When the work of these researchers are taken together, they result in a number of important overall conclusions: First, clients who self-direct their own care have more control and express greater satisfaction over the services they choose. Second, participants in these state programs perceived either that quality improved as a result of consumer direction or at least did not suffer vis-à-vis agency-provided care. Third, the use of independent home care workers, including family members, was frequently associated with increased hours of service per participant, as well as lower total costs of in-home care.

The emerging experience in Arkansas, one of the three states taking part in the aforementioned federal demonstration of cash and counselling, suggests that this particular model—akin to efforts in Austria, Germany and the Netherlands—offers several other important benefits. According to recent findings [39], clients involved in the program were less likely than control group members to have unmet needs; were at least as safe from adverse events and health problems as participants receiving traditional, agency-directed services; and, were more likely to be satisfied with life than the controls.

Lessons, issues and implications for integrated systems of care

Consumer direction represents an important strategy to enhance access to, and the quality of, home and community services for the disabled population in need of long-term care. Our review of consumer-directed home care programs in Austria, Germany, the Netherlands, and the US, as well as findings from research studies undertaken in these countries, support the belief that the frail elderly and younger persons with disabilities would experience a better quality of life if such programs were made more widely available.

Not everyone wishes or has the capacity to manage his or her own care (e.g. persons with cognitive impairment and some of the frail elderly). Nonetheless, the lessons from these programs are overwhelmingly positive. Irrespective of the models implemented, they provide recipients with more choice and control in everyday living, help to ensure greater flexibility in services, produce a higher level of satisfaction and well being, and may be more cost-efficient than agency-directed care.

Consumer-directed philosophy and methods offer a potentially powerful tool to remake care of the elderly and persons with disabilities or chronic conditions. But are consumer-directed care and integrated care antithetical? More specifically, should and can we incorporate consumer-directed approaches in emerging integrated care models? This is an important issue, because integrated systems of care tend to concentrate managerial responsibility and, thus monopolise consumer control, in order to produce the much hoped for end-results of co-ordination, continuity, and cost-effectiveness.

Active discussion of this issue and early experimentation with hybrid models has already begun in the US. American experts are somewhat divided with respect to the need to combine, and the compatibility between, these two approaches. According to a study by Simon-Rusinowitz and colleagues [40], many of the policy experts they interviewed believe that the prevailing medical ethic and obvious tensions between consumerism and managerial/clinical control would present major obstacles to the creation of self-directed managed or integrated care models. However, Kodner and Kay Kyriacou [12], Stone [41], Kodner, Mahoney and Raphael [42], Kodner, Sherlock and Shankman [43], and Meiners et al. [44] demonstrate that integrated systems of care can be fertile ground for consumer-driven services. These authors maintain that such options could “humanise” integrated care by encouraging more flexible service use and greater consumer satisfaction and quality—without harming inherent efficiency and effectiveness goals.

A broad array of approaches or methods is available to encourage and support personal choice, control and self-direction in integrated systems of care:

- New programs could be designed with the active participation of prospective clients and carers in the targeted risk group. In addition, structures could be incorporated into the design to either share program “ownership” with clients or at the very least assure that their voices are clearly heard on the administrative, clinical and service delivery levels.
- Staff development could focus on the recruitment of team members who respect the philosophy of client empowerment. Training could also be developed to help staff overcome the traditional health care mindset with its tendency to dismiss active consumer involvement [45].
- The use of value-driven assessment tools could assist clients and family carers in articulating goals, preferences and expectations from their own perspectives, thus allowing for more personalised, consumer-sensitive and client-driven care [46].

- Information and education services could be provided to enhance the client's capacity to make more informed decisions about service needs and choices [4].
- Clients could be given more control over provider selection, as well as the scheduling of services. Or, more extensive consumer-directed options could be offered, ranging from the use of vouchers to "cashing out" benefits—with or without the involvement of counsellors or professional care managers. The positive experiences associated with the latter approach have been described extensively in this article.
- The incorporation and use of technology in integrated systems of care could greatly enhance the quality of client-provider communications, as well as consumer-directed information and decision-making, thus making empowerment easier to achieve.

To be successful, integrated care programs must do a better job of managing services and costs for disabled and chronically ill persons than the disjointed

systems of health and social care they are intended to replace. Also, they must demonstrate ultimate consumer acceptance and satisfaction. This can only be accomplished by reconciling two seemingly conflicting perspectives, namely, the commitment to professional dominance and managerial efficiency, and the legitimate claims of client autonomy and self-direction.

With mounting evidence on the advantages and positive effects of consumer direction, a strong case can and should be made for the "integration" of this innovative idea and approach into emerging models of integrated provision for people with disabling or chronic conditions in need of long-term care. Whether such initiatives are targeted to working-age or elderly populations, policy makers, planners and service managers would do well to encourage the design of programs and packages of care that incorporate as many of the above features as possible. Further research would also be helpful in establishing the cost-effectiveness of the various consumer-directed models, and in studying how they specifically perform within the framework of integrated service delivery.

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