
Consumer-Directed care A way to empower consumers?

Dr Jane Tilly and Glenn Rees

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Introduction

This publication provides a resource to help those with an interest in aged care to reflect on whether overseas experience with Consumer-Directed care (CDC) has relevance in the Australian context. It has been produced now to support the seminars to be given by Dr. Tilly in Australia during July 2007 and to contribute to the policy debate surrounding community care as part of the implementation of the ***The Way Forward***.

The paper is not suggesting that Australia should import a new model of care. The welfare and care systems in which CDC has been developed overseas are very different to the Australian context. Rather the paper suggests ways in which the influence of CDC may be extended in Australian programs and services to increase consumer choice.

This is a good time to reflect on CDC in Australia. For over 20 years, successive reforms in aged care have responded to the key policy objectives of enabling older people to stay at home and to have greater choice in services. Moreover, in recent years there has been increasing government funding for the development of community services that support consumers in staying at home for longer.

The key question now is whether consumers and service providers see advantage in exploring the notion of increasing consumer choice through the provision of cash, vouchers or budgets in place of agency services. To foster this debate, this paper puts forward some options within which greater consumer choice might be facilitated.

Given an interest in exploring the concept, the paper proposes some well designed pilots as the way forward to explore in an Australian context the many issues that need to be addressed. To enable that to happen governments would need to commit to some degree of greater flexibility within existing program design and funding arrangements.

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Glenn Rees
National Executive Director
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Executive Summary

The objective of Consumer-Directed care (CDC) is to give the persons cared for and their carers more choice and control over their community care than they have with agency programs. CDC is not one model of care but a spectrum of options that extends from agency services and care management at one end to cash and vouchers at the other.

Under CDC, participants may be able to choose which services they receive, who will deliver these services, and when. Participants may be able to manage an individual budget for services. In some models, participants use the funding to hire friends or family to provide care. This paper presents information about the benefits of CDC for people with dementia and their carers. It also discusses ways to make CDC programs dementia-friendly and the potential for Australia to integrate CDC principles into its community care programs.

People of all ages with disabilities and their carers, including dementia families, generally benefit from participation in CDC. International studies of these programs across a number of different countries with varying cultural traditions and programs show that:

- Program participants of all ages and their family carers have better outcomes related to quality of life, independence, and satisfaction with care than those who rely on home care agencies.
- Quality of care is at least as good in CDC programs as it is in traditional programs.
- There is no systematic evidence of abuse or neglect of participants in CDC programs.

Given the evidence of CDC's positive outcomes, it may well be that Australians with dementia and their families and carers could benefit from access to this type of control over their own care. However, these families face some special challenges when participating in consumer directed programs because of the complex symptoms and progressive decline in cognitive functioning that are the hallmarks of dementia and the special challenges that family caregivers face.

At some point in the course of their disease, most people with dementia experience changes in personality and may become withdrawn and depressed, experience agitation, or wander away from their homes unsupervised. People with advanced dementia need help with bathing, dressing, using the bathroom, eating and other daily activities. Carers of people with dementia face physical, emotional, and financial stress.

Despite the challenges, people with dementia and their carers are capable of participating in CDC programs. Carers benefit from the ability to tailor care to the needs of their loved ones and their own needs for support. In addition, people with dementia retain the ability to indicate who should make decisions on their behalf and to make their preferences about services known and to identify someone they wish to have handle health and personal care decisions for them.

In CDC programs it is important to ensure that carers of people with dementia have the help they need to manage services and assure quality. This type of help involves identifying participants with dementia and ensuring they have representatives who can act on their behalf; providing assistance to carers, ensuring that program staff have dementia care expertise, and monitoring quality of care.

Applicability in Australia

In the paper by Howe written for Alzheimer's Australia in 2003, "Is Consumer-Directed care a direction for Australia?"¹ Howe explored the common features of CDC and the relevance of different models to the Australian scene. Howe concluded that "CDC is best seen as one option among many when looking to innovations in Australia" and that we need "to graft them on to the elements of consumer direction that already exist in our own programs and so grow our own hybrids that are suited to local conditions and that will strengthen the culture of our care."

Interestingly, that is exactly what happened in the reform of community care services in Australia in the mid 1980s.

Community options projects were established in Australia drawing on the principles and practice of innovative services in the United States. Overseas writing on the concept of a "nursing home without walls" led to experimentation with hostel options which in turn led to Community Aged Care Packages and Extended Aged Care at Home Packages. And today there are service providers with innovation and flair who want to explore the potential of CDC in an Australian context.

Arguably Australia is well placed to experiment with Consumer-Directed care because it has a comprehensive community care system. Alzheimer's Australia has taken the view that in principle CDC may be attractive to some people with dementia and to their families and carers and that the best way forward is to test a range of approaches so that we can be better informed about its workability in the Australian context.

The approaches to select from could include:

- Making the brokerage options we have work better at the professionally managed end.
- Providing cash, vouchers or budgets in place of the current packages that can be used for the services of the person's choice.
- The more radical step of giving people with dementia and their carers genuine choice between residential and at home care – between residential low care and high care and CACPs and Dementia EACH/ respectively.
- Allowing carers to choose how "brokerage" funds are spent for respite.

Through testing different approaches we can learn something about the more sensitive issues in developing CDC including quality assurance, counselling and care management assistance and eligibility. And, most importantly, we need to learn the views of Australian consumers and whether they have an interest in having the responsibilities that go with greater control over the care provided.

Consumer-Directed care - A way to empower consumers?

Introduction

Consumer-Directed care (CDC) programs give participants and their representatives more choice and control over the delivery of services than in traditional programs where control is in the hands of professionals. Depending on the program, consumers may be able to choose which services they receive, who will deliver these services, and when they will be delivered. They may even be able to manage an individual budget for services. This paper discusses the benefits of CDC programs for participants, and their families and the ability of people with dementia to express their preferences regarding care. It also discusses whether the concepts underlying CDC should be tested in Australia.

The research reported in this paper suggests that CDC may result in better care and greater satisfaction for participants and their families than those who receive services from home care agencies. CDC also can enhance the quality of life for participants and their family carers, who feel that they have more control over how things are done. These benefits are accompanied by increased responsibilities, which may include choosing services and managing, training, and paying workers, and assuring the quality of services received.

These responsibilities are likely to be difficult for people with dementia to manage without help because they often have or develop deficiencies in decision-making capacity and communication. At some point in the course of their disease, people with dementia are likely to experience changes in personality and may become withdrawn and depressed, experience agitation, or wander away from their homes unsupervised. People with dementia will eventually need help with bathing, dressing, using the bathroom, eating and other daily activities. In the final stages of the disease, people lose their ability to communicate, fail to recognize loved ones, and become bed bound. An estimated 20% of people receiving care in Australia's community care programs have dementia.²

Despite the challenges, people with dementia and their carers are capable together of participating in CDC programs. People with dementia, unless they have very severe impairments, retain the ability to indicate who should make decisions on their behalf and to make their preferences about services known. A study of 51 pairs of older people with cognitive impairment and their caregivers living in the community found that individuals with mild to moderate cognitive impairment are able to respond to questions about preferences for care and their involvement in making decisions consistently over time.³ Almost all of people with mild to moderate cognitive impairment were able to identify someone they wished to have handle health and personal care decisions for them.⁴ Seventy-four percent of these individuals named their primary family caregiver as the person who should be making these decisions and most individuals preferred help from family and friends, compared to having to rely on a paid worker.

Consumer-Directed care Program Outcomes

Research indicates that people with dementia and their carers can benefit from participation in CDC programs. In international studies, CDC programs perform well in comparison with community care programs that rely on home care agencies to manage and deliver services.⁵ Elderly and non-elderly program participants and their family carers have better outcomes related to quality of life, independence, and satisfaction with care than those who rely on agencies. Quality of care is at least as good in CDC programs. Studies have found no systematic evidence of abuse and neglect of participants in CDC programs. This evidence is particularly compelling because the results are consistent across a number of different countries with varying cultural traditions and programs.

International Studies

Various types of CDC programs have been studied or tested internationally. European studies largely were conducted on programs that are not means-tested; that is, participants do not have to be impoverished to participate, while U.S. studies focus on programs where only poor people can participate.

- Sixty-five percent of Austrians who received a cash allowance reported that it gave them more independence, choice and control in their lives and that they had greater freedom to select their carers.⁶ Although this study did not have a comparison group of people who received services from agencies, it indicates that beneficiaries believed that choice and control is a benefit of the cash allowance.
- In Germany, 76% of beneficiaries chose to receive their benefit in cash, despite the fact that the value of the cash benefit was half that of the benefit available through agencies. Forty-three percent of beneficiaries reported that the quality of their care had improved as a result of their cash allowance, another 55% said that quality remained the same.⁷ Eight-five percent of those who received cash reported that an advantage of this type of benefit is that they could freely decide how to use the funding.
- The Netherlands conducted a randomised-controlled trial of CDC and found that 85% of participants who received cash had the ability to choose and control their services, while only 46% of those relying on agencies could do so. Those receiving cash reported more satisfaction with quality of care.⁸
- A random sample of participants in California's In-Home and Supportive Services Program (IHSS) found that those who directed their own services reported more satisfaction with their services, higher quality of care, and better well-being than those who relied on agency services.⁹ Participants with paid family caregivers reported more of a sense of security and satisfaction with services than those who hired non-family members. Paid family caregivers reported more stress but better relationships with participants than non-family workers.
- The U.S. Cash and Counseling Demonstration used a randomised-controlled trial to test the outcomes of CDC programs in three states. The study found that elderly and non-elderly participants who managed their own services had fewer unmet needs for care, and reported more satisfaction with their care and quality of life than participants who relied on agency services.¹⁰ This group also reported the same or significantly fewer adverse health outcomes. A comparison of older Arkansas participants with and without mental health diagnoses found that Cash and Counseling worked well for both groups in comparison to the control groups.¹¹ The family carers of CDC participants reported less physical and financial strain and less worry about the care participants were receiving.¹² In Arkansas, CDC participants had significantly less use of nursing homes over a three-year time

period than those who relied on agency services.¹³ In the three demonstration states, there was no widespread abuse of participants or improper use of public program funds¹⁴ and counsellors reported few incidents of abuse, self neglect, or financial exploitation.¹⁵ Counsellors also reported their view that representatives generally acted in the participants' best interest.¹⁶

People with dementia participated in these studies, including the randomised, controlled trials in the Netherlands and the U.S. The careful design of these studies and their positive results for people of all ages with disabilities and their carers indicate that people with dementia could benefit from participation in consumer directed programs.

The example of Mrs. Bennett, a 98-year-old widow who lives with her granddaughter illustrates how CDC can be helpful to dementia families.¹⁷ Mrs. Bennett has mild dementia, high blood pressure, and needs help with three daily activities and walking. Mary, her granddaughter, is Mrs. Bennett's representative. Before enrolling in Consumer-Directed care, Mrs. Bennett received care from Mary and a home care agency. The agency's hours were such that workers came at 8:00 am, even though Mrs. Bennett does not get out of bed until 10:00 am and workers often changed daily and sometimes did not show up for work. With consumer direction, Mary hired one worker – Sylvia—who receives higher hourly pay and a more convenient schedule than she had while working in an agency. Since Sylvia is reliable and her schedule convenient Mary has been able to resume her in-home accounting business. The relationship between Mrs. Bennett and Sylvia is a good one and Mrs. Bennett's family appreciates Sylvia's good work.

Supports for People with Dementia in CDC Programs

Although people with dementia and their carers who participate in CDC programs are likely to benefit from these programs, they will need help with managing their services. The assistance that may be available ranges from very little in some programs like Austria's cash allowance to a range of supports in US Cash & Counseling programs. This section of the paper describes key features of CDC programs that can be made dementia-friendly. These options are drawn from an analysis of US CDC programs.¹⁸

a) Choice

CDC programs could be made an option for people with dementia who receive community care. Having a choice is critical because some participants and their family carers may want to have control over services and others may not want to take on the extra responsibility.

b) Assessment

Most community CDC programs assess the needs of applicants to determine eligibility for the program and how much help a person needs with daily activities, such as eating, bathing, and dressing. During the assessment process, many CDC programs determine whether the participant needs the help of a representative to manage services.

These programs also use the assessment of need process to determine if an individual has cognitive impairment or dementia. If so, the participant is evaluated to ensure that he or she has the help needed to manage services or chooses a representative to manage services. Conditions like Alzheimer's disease cause a person's functioning to decline over time so periodic reassessments of the capacity to manage services are critical.

The strain of being a dementia carer can be overwhelming¹⁹ and family carers often need relief to help them avoid deterioration in their own health or well-being and to

delay institutionalisation of their loved ones. Thus, some CDC programs determine whether the family carer needs help with his or her responsibilities. If the carer does, then the program connects him or her with supportive services that may be available in long term care programs or in the community. Programs could go further and help carers find health care services that they might need

c) Representative Responsibilities

In CDC programs, many, but not all, participants ask representatives to help them manage their care. Representatives generally are trusted individuals who know the person with disabilities well and have a consistent presence in the life of that person. The representative's management responsibilities can include recruiting, hiring, training, and managing individual workers, who might be family or friends of the person with disabilities.

Since representatives could have a great deal of management responsibility it is important for them to understand the consumers' preferences regarding care and follow them to the extent possible. Obtaining this understanding from people with dementia could be difficult, depending upon the level of cognitive impairment and how well the representative knows the person. Representatives may need training to help them elicit the preferences of the person with dementia.

d) Training

Most of the actors in CDC programs need to know how to deal with the special needs of participants with dementia and their families. These actors include program staff, representatives, and carers. The requisite knowledge can be gained through training or demonstrating expertise with dementia care and the principles of consumer direction.

- Assessors and care coordinators should have the skills and knowledge necessary to effectively help participants with dementia and their representatives use CDC programs. Thus, these professionals need to have specialised training or to demonstrate that they have the necessary skills.
- The family carer, who may be a representative or a paid carer, may need training on how to care for a person with dementia most effectively. For example, knowing about strategies for dealing with unsafe wandering or managing challenging behaviours could be very helpful to carers. Therefore, service coordinators should refer carers to sources of specialised training, such as Alzheimer's Australia.
- The representative, carers, and consumers need training on how to handle management tasks, such as how to hire, fire, supervise workers, handle responsibilities for oversight, payment, etc.
- Among the forms of training that assessors and service coordinators should have are methods of recognising signs of abuse or neglect of consumers. If State or Territorial law does not already require this, these professionals should have a mandatory duty to report abuse or neglect to the proper authorities.

e) Quality Assurance

Participants and service coordinators share responsibility for quality assurance. Consumers or their representatives need to hire qualified workers and train them to deliver appropriate care. Service coordinators play an important role too. They are in periodic contact with consumers and their representatives to provide assistance when needed and help with resolving any issues that may arise. An example of how this works came from a state in the US. During routine contact with an older woman with dementia and her daughter, a service coordinator found that the daughter was not able

to handle the increasing demands of her mother's care as the dementia progressed. The counsellor was able to work with the family and arrange for the participant's sister, who is a retired nurse, to take over some of the caring responsibilities.

Quality of care problems will be very hard to detect unless the service coordinator has frequent contact with the participant and his or her representative. Frequent home visits would be the most effective way to monitor care. For participants with dementia, the frequency of visits should not decline over time because a situation that works for the participant and carer now, may be untenable several months later.

Quality assurance systems should ensure that they collect data on quality of care for those with dementia, because this population is more vulnerable to problems than those program participants who can speak on their own behalf. Analysis and reporting of these data on those with dementia is critical.

f) Financial Management

Many CDC programs determine the amount of care that the participant needs and convert it to a monetary budget for community care. The participant, with the help of his or her representative and the service coordinator, then prepares a spending plan for services. There are few restrictions on how this money can be spent, as long as the spending is designed to meet the care needs of the participant. Participants may choose to spend their budgets on workers who come into their home, home modifications, adult day care, housekeeping and other services that will meet their needs.

CDC programs generally provide financial management services that help the participant pay any individual workers they may employ as well as bills for other services such as home modifications. These financial services agencies handle payroll, tax withholding, and related functions. Most participants in consumer directed programs prefer to use these agencies.

Potential for Consumer Directed Community Care in Australia

CDC already exists in Australia through the Carers Allowance. This cash allowance is paid to the carers of severely disabled people and is neither means tested nor taxed. This allowance enables the carer to purchase whatever goods or services are needed. It has no restrictions on the way it is spent.

The concept of people making their own choices about how their Government subsidies are spent is therefore not unknown in Australia. The gradual expansion of this concept into other programs would not represent a "quantum leap" in program design, and there is much to be gained from people making their own choices. CDC programs have the potential to give participants and their carers improved care and quality of life as a result of having much more choice. Many aged care providers in Australia pride themselves on providing "client-centred care." But the consumer view is typically that most services do not allow the person much of a say in the type of care they wish to receive, where they wish to receive it or how it is provided. In other words they do not feel in control of their lives

Australian community care programs could test integration of CDC principles into their well-developed systems. For example, Australia provides federal funding to assist State and Territory Aged Care Assessment Teams who assess eligibility for institutional long term care services. The teams' assessments cover medical, physical, social, and psychological needs, including cognitive functioning and the presence of dementia. These teams also provide advice about care choices. If consumer-direction were to become a choice in Australia, these teams could assess an individual's capacity to direct care and the type of assistance he or she would need to be able to do so.

Australia has three community care programs that serve older people with dementia in their homes and communities; funding comes from federal, state, and territory budgets. The *Home and Community Care Program* (HACC) provides services such as community nursing, domestic assistance, personal care, meals, home modification, and respite care. *Community Aged Care Packages* (CACP) provide a home-based alternative for older people who would otherwise need low level residential care. *Extended Aged Care at Home* (EACH) packages provide services for people needing high level residential care. Dementia EACH packages provide services for people with dementia and challenging behaviour who would otherwise need high level residential care.

Each of these programs already has a degree of CDC built in, in that the case manager receives a cashed out benefit with which to provide or purchase services for the care recipient. It would only be a small step to allow the care recipient (or the carer), to manage his or her own care in some cases with this cashed out subsidy.

Not every care recipient would want this option, but for those who do, there is a greater chance of users being able to obtain services they want, when they want them.

Another example of where Australia is already close to a CDC approach is found in the brokerage funds available through the National Respite for Carers Program. Brokerage funds are already available for Carer Respite Centres to spend on behalf of clients. It would be only a small step to allow carers and their loved ones to determine how Carer Respite Centres spend the money.

A more radical experiment would be to allow people to decide whether they wish to have their care provided at home or in residential care. Consumer preference for staying at home is often quoted but not often put to a real test. Australia's subsidy systems for both residential care and packaged community care are already closely aligned, and it would not be a radical change to experiment with merging, say, the subsidy for residential low care or high care and the subsidy for community aged care packages or EACH, and allowing the recipient to determine where they wish to be cared for.

Of course no wholesale change to Australia's aged care system should be considered until new approaches such as these have been piloted and properly evaluated. Overseas evidence suggests that such pilots could be very rewarding, both in terms of discovering new and better ways to deliver care and in terms of better outcomes for people receiving care. The challenge to governments is to devise the flexibility in program arrangements that might make this possible.

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The February 2007 issue (volume 42, number 1) of Health Services Research is devoted to the research results of the US Cash & Counseling Demonstration.

For more detailed information on the U.S. Cash & Counseling demonstration project and the research results please visit www.cashandcounseling.org.

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