

AGED CARE SERVICES 28 OCTOBER 2010
CONSUMER DIRECTED CARE
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Thank you for the invitation to talk to you today about Consumer Directed Care – or CDC.

I expect, by now, many of you have a pretty good understanding about CDC. And some of you, at least maybe be taking part in some of the new CDC packages that have been funded by the Commonwealth Government.

Since the reforms of the mid 1980s, consumers have been looking to aged care services to provide the mix of services to meet their needs to have the choice to remain at home for as long as possible.

Some services have sought to achieve this by diversifying across the range of community and residential services. They are I believe better positioned to respond from a consumer perspective to the needs of older people, as there is no need to deal with more than one organisation as their care needs change.

Alzheimer's Australia has advocated for a CDC approach for almost 10 years.

Alzheimer's Australia first set out in 2001 to inform the CDC debate with a paper by Dr Anna Howe, ***Is Consumer Directed Care a direction for Australia?***

Anna said two things in that paper which I think still resonant as key issues. First, it is important to think and develop CDC in the Australian context and not to make the mistake of simply slavishly copying others.

Secondly, Anna warned that older people might not want to be employers of care staff. And that the cash option might not be the preferred option for many older people.

We followed that paper up with one jointly authored by Dr Jane Tilly and myself ***Consumer Directed Care: A way to empower consumers?*** in May 2007 and at that time arranged a series of seminars across Australia with family carers and people with dementia to discuss CDC and get some first reactions.

The response was overwhelmingly positive and we were encouraged to take our advocacy to the government and the Department.

While we would have liked the issue to have moved rather more quickly, we are delighted that the Commonwealth Government has funded selected community aged care providers to fund CDC packages and respite CDC places.

A slow start perhaps, but an important one in terms of setting the scene for the reform of aged care.

The evaluation tender for the CDC places has, I understand, been decided but not yet announced. A good evaluation will, I think, be helpful to all of us, much as the evaluation was in the context of the development of the Extended Aged Care and Home packages in the late 1990s.

In the time available, I would like to:

1. Explain what is meant by CDC and why we seem to find the concept so difficult.
2. Identify some of the reasons for which CDC is important from a consumer perspective.
3. Identify some of the issues that CDC raises.
4. Place CDC in the context of the broader reform of aged care.

What is CDC?

There is no one definition of CDC

I believe the objective of CDC is to enable the care recipients and their carers to have greater control over their own lives by allowing them, to the extent they are capable and wish to do so, to make choices about the types of care services they access and the delivery of those services, including who will deliver the services and when.

I stress that CDC is about having the choice to exercise choice.

CDC is both a philosophy – the right of consumers to choice – and a spectrum of options that extends from consumer participation in the planning and delivery of agency services to budget holdings by the service provider for use by the consumer to cash or vouchers.

Some service providers would consider that they are already achieving the philosophy that is embedded in CDC by promoting consumer participation in service planning.

The spectrum of options causes some confusion in identifying what the issues are that people are raising as they translate CDC into consumer participation in agency delivery, budget holdings or cash. In my experience, most of the issues that are

raised relate more to cash than to carers being an equal partner in the planning process or the concept of budget holding.

There is nothing new about the principles that underpin CDC. Overseas CDC approaches date from at least the late 1980s. In Australia, the concept is familiar and part of disability services.

Aged Care policy since the reforms of the middle 1980s has been premised on the assumption of providing support for consumers in their choice to stay at home, as well as services that are responsive to their needs. The reality is that most consumers do not feel that they are in a position to influence service provision.

I read last week a paper by the Alzheimer's Australia Vic consumer advocate committee entitled Rhetoric versus Reality – The Chasm for Dementia Consumers. As the title suggests there is frustration, disillusion, frustration and anger about how the current provision of aged care packages works.

Frustration that they do not know what the funds are available to meet their needs. Confusion about how service providers allocate funds to individuals from available package funding. Anger about the administrative expenses that can account for a high proportion of available funding – up to 50% they say.

This is so despite the fact there is nothing new in principle in CDC. The introduction of 'community options' kinds of programs in the late 1980s, embedded the principle of choice by empowering the consumer to have access to those services that would best support them to stay at home in planning the care to be provided.

Disability services in Australia and elsewhere have embraced the concept in providing cash.

International studies of CDC programs for people of all ages in a number of different countries with varying cultural traditions and program structures have shown that:

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

I acknowledge that views differ about the adequacy of the evaluations overseas and it will be important as I said at the outset, to learn in the Australian experience, how CDC can best be implemented and what lessons can be learned.

Consumer perspective on CDC

The reality and the potential of consumer choice depend quite simply on two things:

- Firstly, a change in the balance of power between the consumer and the service provider, so the consumer is able, if they wish, to decide their care options.
- Secondly, service providers having the flexibility within program structures and funding to respond to the expressed preferences of consumers.

And of course there will be a challenge for bureaucrats in not imposing accountability and program guidelines of a kind to a degree that the concept is mangled and choice becomes a mirage.

Some of the questions that get raised by consumers perhaps will illustrate better than I can, the importance of consumer directed care.

Why should a family carer who wants to attend church on Sunday be denied respite because the service does not operate at those hours or cannot provide the one and half hours respite necessary.

If a person with dementia likes getting up early, why should the support the person needs, not be available until agency staff are available later in the morning?

If a person with dementia and their family carer have a set objective of remaining in the community for as long as possible, and possibly until death, why should the consumer be offered a residential care place rather than a community based high care package?

If a person from a culturally and linguistically diverse background or Indigenous person knows a person in their family or community network who could provide respite and care, why should they not be able to ask the service agency to employ them, or to be referred by the service provider to a more suitable or acceptable agency?

If a person with dementia and their family want to plan on an ongoing basis of two month residential respite and two months in the community, why should it not be possible?

Why should a younger person with dementia who does not want to enter a care centre for older people, not have the opportunity to access more appropriate forms of respite, for example, to be accompanied to an activity of their choice?

CDC in terms of those questions is as much about flexibility, in service delivery as it is about a new model of care. And I of course recognise that from a service provider perspective, flexibility is an issue given differing program arrangements and restrictive guidelines.

But if the dream is person centred care and responding to the needs of the individual, then it seems to me that empowering the consumer through CDC to be an equal partner in the determination of the care options is not only desirable, but unavoidable.

The lack of consumer empowerment perhaps is one of the reasons why we have struggled so much with the achievement of person centre care approaches.

The issues

We are at the point in Australia in aged care where we are not debating whether CDC should be embraced, but how to do it. And there are important issues to address, both from the perspective of consumers and service providers.

It is the cultural issues and values that seem to me to be the most difficult in the successful implementation of CDC.

First for carers and their families, service providers and the community more generally, to be less risk averse in supporting older people to live their lives the way they wish to. It is frequently acknowledged that the baby boomers as they age, may well be more assertive and less risk averse. How are we going to come to terms with that?

Second, for service providers, CDC requires not only changed and more flexible program structures, but cultural change in the way service providers develop their relationship with older people. Consumers will be informed about the budget available for them.

Beyond those considerations there are detailed issues that will require attention in the evaluation of CDC:

- The strategies that work best in informing consumers about what services are available and how to make choices.
- The assistance consumers need in planning and contracting their choice of service support.

- The capacity of the service system to respond to choice.
- The cost implications of CDC for example as a consequence of substitution effects for informal care or individualised services needs.
- Ensuring that the quality of services delivered under CDC are at least as good as those generally available.
- The ways in which CDC can be developed to give people from CALD backgrounds and indigenous people the flexibility they need to access services that are appropriate including by employing people from their own communities.
- Whether budget holding gives consumers the flexibility they need or whether cash options should be considered at a later stage.
- The administrative consequences for service providers in administering CDC.
- Evidence of any abuse of older people as a consequence of CDC.

An area of service delivery that I believe will be particularly interesting in terms of CDC and the evaluation is respite care.

Respite care is a crucial component of support for carers and can enable individuals with dementia to continue to live at home for as long as possible. Unfortunately, many family carers of individuals with dementia have difficulty accessing respite services that meet their needs.

For every three carers who have used respite, there are two dementia carers who need respite but have not used it.

Based on the Alzheimer's Australia publication, 'Respite Care for People Living with Dementia' Alzheimer's Australia made a number of recommendations to the Productivity Commission Inquiry to aged care regarding improving the flexibility and access to respite.

Alzheimer's Australia has suggested that carers not only want a break from providing care but also want services that meet the needs of the person with dementia, including age and culturally appropriate social and community engagement.

We have recommended the transfer of funding for residential respite care to the National Respite for Carers Program to be used as brokerage funds that can be applied flexibly to meet consumer needs for different kinds of respite services.

Aged Care Reform

CDC is not a panacea. To the contrary it only makes sense in the longer term if there is reform of aged care that involves structure change in programs and improved access to community and residential care.

There is nothing new in the notion of choice in the sense of enabling older people to stay at home for as long as possible. What has been missing I think, is the realisation that that choice is, in practice, denied to older people as a result of restrictive program structures, divided Commonwealth and State responsibilities and a lack of consumer empowerment.

It is encouraging that the National Health and Hospital Reform Commission adopted increasing choice for older people as the theme for their recommendations in aged care.

And the Productivity Commission have been refreshing in their commitment to look at the reform of aged care from the perspective of the older person.

The point is that CDC, although important, will amount to little unless a national aged care program is successfully implemented; there is better networking and delivery of information and streamlined assessment processes and a separation of accommodation and care so that consumers have genuine choice in the mix of community and residential aged care that is appropriate to their needs.

The notion of choice will be illusory if there is not the opportunity for choice between community or residential care or a mix of the two.

Strategies are needed to increase diversity and geographic accessibility for true consumer choice.

In another senses CDC is critical because it embodies introducing into aged care the radical notion that older people have a right to determine for themselves what care and support would best enable them to remain independent and at home for as long as possible.

We have been a little slow to realise that giving choice without the power of decision means very little. If consumers do not know what funds are available to help them on the basis of assessed need, they're not in a position to be a genuine partner in the decision making process.

Conclusion

CDC holds out real promise as well as real challenges. For consumers it means being prepared to exercise choice and to be informed in exercising those choices.

For service providers the challenge will be to embrace an equal relationship in service delivery with older people.

For the political level and bureaucrats the challenge will be to give the system both consumers and service providers, the flexibility needed to exercise choice and to avoid mangling an exciting concept with excessive bureaucracy.

The language we use to talk about CDC is complex because it embraces a wide spectrum of service activity. It ranges from the notion of consumer sovereignty in giving the consumer cash to consumer engagement in care planning at the other extreme. In the middle, there are options including budget holding by the provider with the older person or their family carers doing the case planners role.

I suspect over the coming years we will come back to one simple question that will be hard to answer. How much choice do consumers want to exercise and how much are service providers and bureaucrats prepare to allow them?