

**AGED CARE SERVICES 4 May 2011**  
**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 good understanding about CDC and are probably adopting CDC principles. Some of you may be taking part in some of the CDC packages that have been funded by the Commonwealth. The Commission's Report is valuable not only in advocating change but the extent of change required to achieve greater choice.

The elements highlighted in the draft report of the Productivity Commission that illustrate the extent of change required are

- A radically different approach to the provision of information and assessment services
- A shift from rationing aged care places to providing aged care as an entitlement to those that need it
- The separation of accommodation and care
- The rebalancing of the system in terms of community and residential care

The recent release of the Draft Productivity Commission Report has given me another opportunity to consider CDC: what it means, where the boundaries are set around choice and why, and the direction we are headed.

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 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 not everyone might want the same level of responsibility and control over budgets.

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.

We would have liked the issue to have moved rather more quickly, but we are pleased that the Government has started to take some action- even if it is just dipping our toes in the water.

As you know, the Commonwealth Government has funded a trial of CDC packages and respite places.

An evaluation of the CDC places will be undertaken by KPMG. An evaluation of progress so far will 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 January, the Productivity Commission released their draft report on the inquiry into aged care. This report was yet another step forward, as the principles outlined in it focus on providing greater choice and flexibility, a greater emphasis on community care and a separation of accommodation and care.

We wait in anticipation for the release of the final report, and the governments' response.

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 the benefits and the risks posed by CDC.
3. Explore how CDC fits in the context of reform of aged care.
4. Discuss where we go from here.

### **What is CDC?**

There is no one definition of CDC

The key to CDC is the provision of choice.

Some of the questions that get raised by consumers perhaps will illustrate better than I can, the importance of real choice.

Why should a family carer who wants to attend church on Sunday be denied respite because the service does not operate at those hours? Why shouldn't that carer be able to employ a friend to provide the much needed respite?

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 care and would be able to speak the care recipients language why should they not be able to ask the service agency to employ them?

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 by a neighbour to an activity of their choice

In my words CDC is both a philosophy and an orientation to service delivery that acknowledges that consumers have a right to choice.

The main goal of CDC is to offer consumers greater control over their own lives by providing them with the opportunity to make choices about their care, to the extent they wish to do so.

The points of difference emerge once we move beyond broad principles to the practical questions of how you provide choice, how much choice should be available, and how risk is managed.

In practice- CDC describes a continuum of choice and consumer involvement on a number of dimensions of care including 1) care planning 2) budget holding 3) service delivery.

Involvement in care planning can range from providers taking into account consumers preferences, skills and goals when developing a care plan to a partnership approach where the care recipient is directly involved in planning.

Budget holding can range from vouchers for care, individualised budgets which are held by providers, to a fully cashed out system in which care recipients can use funding to purchase care services themselves.

Service delivery can range from being able to choose your provider from a list of 'approved providers' to having the option to purchase care or respite services from family or friends.

As you can imagine- going across these three dimensions and the various types of choices that can be available under each- CDC can begin to mean many different things.

The different uses and meanings of the term CDC can create confusion. Providers may think they are providing CDC by involving consumers in care planning- but consumers may be disappointed when they are unable to have the full set of choices across all three dimensions that they may expect.

In my experience, most of the points of difference raised relate more to budget holding or who provides services than to carers being an equal partner in the planning process.

Many consumers would say that consumer directed care should mean that they can determine what services they need, who should provide them, and when and where they are provided.

Much of what is labelled as CDC falls short of these expectations.

The reality and the potential of consumer choice depends 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.

CDC is as much about flexibility, in service delivery as it is about a new model of care.

### **Is CDC a new idea?**

There is nothing new about the principles that underpin CDC. CDC can be traced to the disability rights and self-determination movements in the UK and US in the 1970's that led to deinstitutionalisation of individuals with disabilities and moved towards independent living programs. Some date CDC further back to the 1950's when a home care program for polio patients was developed in the US as an alternative to more costly hospital treatments.

In Australia, the concept is familiar and has long been a part of aged care reform and 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 providing 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.

Disability services in Australia have had a more rapid uptake of CDC principles. Most state and territories now have some type of budget holding scheme for disability services. This is likely to be further expanded given the recent recommendations of the Productivity Commission with regards to disabilities.

### **What are the benefits and risks of CDC**

There is relatively good evidence to suggest many positive benefits of CDC.

In fact the Productivity Commission, in their disability report stated: "There is widespread and compelling evidence that it leads to good outcomes (in life satisfaction, confidence in their care, feelings of control, health, employment, a variety of other wellbeing dimensions, and potentially all at lower cost)."

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 have a greater sense of independence, choice and control
- Greater satisfaction with care
- Quality of care is at least as good as CDC programs as it is in traditional programs.

For example, there is evidence of good outcomes from the US Cash and Counselling Demonstration project.

In this program, individuals seeking care services were randomised to either a group that received a cash budget to purchase services or to traditional agency services. Most individuals in the cash group chose to get care from friends or relatives.

Individuals in the cash for services group had greater satisfaction with performance of the carer, and the relationship with the carer than individuals receiving traditional services. They also had greater reductions in unmet needs for help with household activities and transportation.

The cash system was shown to be at least as safe as agency directed care in terms of adverse events and individuals receiving this care had similar health outcomes as those receiving traditional care from accredited providers. There was also no evidence of abuse, with fewer instances of theft by caregivers in the group receiving care from cash.

So what are the risks?

It is inevitable that with choice comes some degree of risk.

If individuals are provided with a cash budget to access services- there is the concern that they will be taken advantage of by relatives or will spend the money on something other than care and still require services.

There is no evidence of systematic abuse or neglect of participants as a consequence of CDC. In fact international evaluations of CDC suggest that the risks associated with cash options are manageable and even comparable to the risks associated with normal agency services.

There is also the risk that some consumers will not be comfortable with the responsibility associated with having more choice. It is important to note that CDC should always be about the *option* of greater choice, with the understanding that some consumers will always prefer the traditional agency delivered services.

### **Aged Care Reform**

So given that there are clear benefits to CDC, the big question is how CDC fits into the reform of aged care in Australia. 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 what the barriers will be around choice.

To date- CDC in Australia is a somewhat watered down version of what has been tried in Europe and the US.

The CDC packages have provided an opportunity for consumers to be involved in planning and determining their care needs. But they have not allowed consumers to be budget holders or to access services beyond those of traditional providers.

From anecdotal reports of service providers who are managing the CDC packages, it seems many consumers are disappointed at the level of choice provided.

Going forward- this seems to be the model of CDC that Australia is adopting. One of the underlying principles of the Productivity Commission's inquiry into the reform of aged care was "Be consumer-directed, allowing older Australians to have choice and control over their lives".

If the Commission's recommendations are implemented, individuals would be given an 'entitlement' for care which they could use for purchasing services from amongst a set of "approved providers". This is a marked shift from the current system of rationing and is a positive move towards greater choice. But again- individuals would not be able to cash out their entitlements or access care from friends, family or other members of the community.

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. If there are no services that provide appropriate care, particularly for those from diverse backgrounds or who have younger onset dementia, then what kind of choices do individuals really have?

In this context, we must remember that the 'compelling evidence that choice leads to good outcomes' is from evaluations of much more liberal programs which provide much greater choice. We must expect that outcomes from the Australian version of CDC will differ at least in degree.

It is interesting to note the difference between the choices that are offered in the disability sector and those in aged care. It becomes even a starker comparison when we consider individuals with younger onset dementia who may have greater choices about their services until the day they turn 65.

It seems we are more risk adverse as society to giving older people choice than people with disabilities.

I am not sure why that should be but it seems to be assumed that older people do not want greater responsibilities for their care and that it is just too risky to provide these kind of choices to older people.

I doubt we know enough about the attitudes of the current generation of older people or those of the baby boomers to make such assumptions on the part of all older people who may need care.

And I suspect we all need to re-examine our attitudes and the reasons for which we seem so risk adverse in respect of allowing older people to live their lives the way they wish.

### **So where to from here?**

We are not debating whether to do CDC but how to do it.

In its response to the Productivity Commission Alzheimer's Australia has advocated that there is a need to provide older individuals with the same level of choice that we see in the disability sector, particularly for respite and for individuals from diverse backgrounds and rural and remote areas.

We have put forward two lines of argument.

First, that unless there is an evaluation of a cash option we will never know what the implications are in the context of aged care and the attitudes of older people. Such an approach would prepare the way for the future.

We do not expect the cash option to be adopted tomorrow but let's not wait another 25 years.

Second, that 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. It is the context in which we would most like to see innovation and greater flexibility in service delivery including the cash option.

This is because 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.

Providing individuals with options to employ friends, family and other members of the community will open up options for carers and will enable them to keep continue to provide care for the person with dementia in the community.

Experimentation with cash in aged care programs and particularly cash together with other work including the evaluation of the CDC trials will contribute to future decision making as the aged care reforms are implemented in a number of areas:

- 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.
- The administrative consequences for service providers in administering CDC.
- Evidence of any abuse of older people as a consequence of CDC.

These thoughts I think take me full circle in my thinking on consumer directed care.

When Warwick Bruen and I started thinking seriously about consumer directed care and what it might mean in the Australian context our first thoughts were that the potential greater flexibility and potential for consumer empowerment that CDC offers would be of most assistance to those groups at greatest disadvantage in accessing funded aged care services.

Perhaps one of the more innovative aspects of the Alzheimer's Australia response to the draft report of the Productivity Commission on Caring for Older Australians was for the first time to avoid an "add-on" last section headed "special groups". Over the years we have all nodded in the direction of special needs but failed to do what I believe those diverse groups want and that is to be part of main stream – not an after thought in submissions.

So our approach is now to deal with the range of social, cultural, religious and linguistic differences among diverse client groups by trying to ensure they are part of our consideration of how all Australians access and receive services through the aged care system.

Our view is that an understanding of diversity and equity needs to permeate the way we think about developing and delivering quality services that will meet the needs of an increasingly diverse ageing population.

The approach that I have discussed on where we go from here with its focus on cashing out and respite seems to me to offer the flexibility that diverse groups need to access services available to other Australians.

It may be that it is worthwhile testing the hypothesis that greater flexibility and empowerment in delivery of programs to diverse groups will do the job more effectively than providing limited additional funding or focussing on one or two important services such as translation services.

It will be common ground between us all that we are not doing well in respect of diverse needs and something more dramatic is needed than the strategies tried over the last few decades.

If we do not embrace some more radical surgery the promise of greater choice for all Australians in aged care services that responds to their needs will be a cruel trick.

## **Conclusion**

Let me conclude by saying that there is no naivety on the part of consumer organisations about the magnitude of change we are seeking or about the need for carefully staged implementation of aged care reforms.

And for some groups and particularly for those with severe behavioural problems, and those with younger onset dementia there are structural barriers between state funded mental health and disability systems and the Commonwealth funded aged care system that need to be addressed and adequate funding provided if there is to be any reality of services let alone greater choice.

There is perhaps is a small window of opportunity for those with younger onset dementia whether with a previous history of disability or not. The Productivity Commission has taken the opportunity to coordinate its important work in respect of both disability services and aged care. And while there is a way to go we are pleased that the starting principle adopted by the Productivity Commission is that “the critical issue is to ensure that people would be able to use the support system that best met their needs, regardless of the funding source”.

I would encourage you all if you have not done so to look at volume 1 of their Draft report on Disability Care and Support section 3.17 – 3.21 of Vol 1 and the discussion of the relationship between the proposed National Disability Insurance Scheme and aged care.

CDC holds out real promise as well as real challenges both in aged care and the disability sector. 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?