

**THE AUSTRALIAN ASSOCIATION OF GERONTOLOGY PRODUCTIVITY  
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**CONSUMER DIRECTED CARE: ADVOCACY, POLICY AND RESEARCH**

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Thank you for the invitation to talk to you today about consumer directed care – or CDC.

I have been asked to speak briefly about my role as an advocate for CDC and the dynamic interplay between evidence and consumer advocacy in the development of policy.

It seems to me the two part argument runs as follows.

The idea and the passion has driven the case for CDC but it has been shaped by research and the evidence.

So let me start with my story – I cannot of course speak for the many others who have helped get CDC on the national agenda.

My story has a beginning, a middle and an end.

**The beginning**

When I joined Alzheimer's Australia as CEO in 2000 I asked myself what we meant by giving the older person the choice to remain at home for as long as possible?

What hangs on the word choice? And had we failed in our design of the reforms.

Where was the commitment to empowering consumers that drives disabilities services?

How could person centred care become a reality when consumers had such limited power?

And where was choice when community services remained the cinderella?

For me CDC is a question of human rights and dignity. I believe that consumer empowerment through greater choice will lead to services which will by definition better meet the needs of the individual.

So in 2001 I did what any self respecting advocate would do and I asked Anna Howe to provide a paper on Consumer Directed Care: A direction for Australia.

Anna's paper proved to be equivocal.

She said three things in her paper that continue to resonate as key issues.

First, that it is important to develop CDC in the Australian context and not to make the mistake of slavishly copying others. And to make the point drew attention to the history of the domiciliary nursing care benefit which had started out its life as a cash alternative to residential care in Australia.

Second, that there was no one model of CDC. Rather it was an idea that could take many forms along the continuum of consumer involvement in planning to budgets held by service providers to cashing out.

Third, Anna warned that many older people might not want to be employers.

### **The middle**

Better informed but not discouraged I returned to the many references Anna had given me and searched for another opinion.

In 2006 I approached Dr Jane Tilly in the United States who had done evaluations of the cash and counselling services in the USA and knew a bit about the different approaches taken in Europe.

The outcome was that Dr Jane Tilly and myself produced ***Consumer Directed Care: A Way to Empower Consumers?***

With Jane's help it was possible to demonstrate that International evaluations of CDC programs such as the US Cash and Counselling Demonstration project 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 in CDC programs as it is in traditional programs.
- Similar health outcomes to individuals receiving traditional services.

There is also 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.

These research findings are mostly from models of CDC that are more liberal than what has been proposed in Australia.

So the next step for me was to find out what Australians thought of CDC. We took to the streets in 2007 and 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. The stories of consumers brought to life the evidence and the difficulty they experienced in accessing respite, culturally appropriate services or services for those with younger onset dementia.

Andrew Stuart was kind enough to arrange a seminar in the Department which I am sure helped get the ideas more widely understood and eventually embraced.

The seminars were written up by good friend and former colleague the late Warwick Bruen. Warwick who was committed in all his work to getting a better deal for consumers was able to blend conviction with policy realities and evidence.

The report not only articulated what is meant by CDC but also went further in promoting CDC in care packages, adopting the principle in the context of separating accommodation and care and the potential for greater consumer choice in respite care.

I took the debate to the National Aged Care Alliance and service provider organisations were kind enough to give me opportunities to present and discuss CDC.

Talking through the issues in those forums helped a great deal in getting a clearer idea of the different perspectives of service providers, unions and other consumer groups.

We were now positioned to take the argument to the bureaucratic and political level.

### **End game**

In their 2008 Trends Report the Productivity Commission traversed many new ideas and included CDC. They were more than generous in quoting from the publications of Alzheimer's Australia. We were respectable!!

Eventually Warwick and I found our way to the Minister's Advisory Committee, the Aged Care Working Group – again with the help of Andrew Stuart.

We were invited to present at that meeting. A decision was taken to recommend to the Minister that a working group be set up to pursue CDC. Perhaps the seminal part of that discussion was a carefully crafted definition of CDC for agreement.

The rest is history and we have had the first tentative steps to embrace CDC in new packages.

### **But the story never ends!**

The role of researchers and evidence starts again now in earnest.

We put forward two lines of argument to the Productivity Commission.

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 in Australia and the attitudes of older people. Such an approach would prepare the way for the future.

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.

I am delighted that the Productivity Commission in their final report on ***Caring for Older Australians*** has taken up the challenge and recommended that cashing out be trialed in respite care.

Experimentation with cash in aged care programs and the evaluation of the CDC trials will contribute to future decision making as the aged care reforms are implemented. We need evidence to inform us on:

- 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.

## **Conclusion**

Like love and marriage ideas and passion and research and evidence need to come together. But the driver I think in the case of CDC was the passion of many for an idea.

Researchers need to help us with the question how much choice do consumers want to exercise and how much are bureaucrats and service providers prepared to allow them