

THE REALITY AND POTENTIAL OF CONSUMER CHOICE
NATIONAL COMMUNITY CARE CONFERENCE
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I should like to thank ACSA for the invitation to speak at this conference and more particularly, for the flair and imagination they have shown as a service provider organisation in putting a spotlight on community care.

Part of the practical expression of this support was the way in which ACSA supported the seminar series Alzheimer's Australia undertook last year on Consumer Directed Care. This and other papers are on the Alzheimer's Australia web site www.alzheimers.org.au

Our own interest in this subject dates from asking Anna Howe in 2001 to do a paper that would help better inform a wider public about Consumer Directed Care and whether it is a direction for Australia.

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 such that 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.

With that in mind, I will focus what I have to say on:

- The current policy context.
- The concept of Consumer Directed Care and the kind of flexibility consumers might be looking for.
- The evidence that supports Consumer Directed Care.
- Options to free up policy and programs.

The Policy Context

Policy has been founded since the mid 1980's on the premise that the preference of older people is to stay at home for as long as possible. Arguably, the focus of policy and program design has been more on expanding the range of services than enabling consumers to make decisions about their own care. The evolution of policy and community programs has been pragmatic and slow. It has involved:

- The birth of HACC in 1985 and the recognition that service silos in the community sector were not helpful to promoting a more flexible, varied and integrated range of services.
- Political processes since then, of course have ensured new silos, notably in respect of respite and the National Respite for Carer's Program.
- The notion of flexibility and community choice was embedded in the community options style of project, which provided the service provider with greater flexibility in the use of funds.

- The advent of packages with hostel options back in 1988, the introduction of Community Aged Care Packages in 1993 and the Extended Aged Care at Home packages in 1999.

Arguably, service provider flexibility and consumer choice is impeded by:

- The limited funding available in HACC
- Structural issues in the provision of Commonwealth funded packages, including the gap in subsidy levels between low intensity and high intensity packages, access to the full spectrum of service types, the inadequate purchasing power of packages and the total funding base.
- The need for a single funding stream for respite across the community care system that would seek to address overlaps in respite provision across the National Respite for Carer's Program and the HACC program.
- The number and complexity of different programs with different guidelines, and the need to move between these as needs change
- The interface between Federal and State programs and different structures across states make national consistency difficult.

These issues and others were identified in the response to the Way Forward and the Review of Subsidies and Services in Australian Government Funded Community Aged Care Programs in early 2007 and raised by the Community Care Coalitions in the Nours and Allen reports. I believe that there is now a reasonable consensus on the action that is needed.

It is uncertain at this time how the new Federal Government will take forward the unfinished work commenced by the Howard Government in reforming community care, including the review of subsidies and services in Australian Government funded community care programs. But Alzheimer's Australia has made a point of arguing, that along with many other issues, Consumer Directed Care should be considered in the reform process.

The challenge then, is to get reform of Community Care the priority it merits in the early days of a new Federal Government.

Making Choices

For a number of years Alzheimer's Australia has advocated that people with dementia and their family carers should have the option of making their own choices in respect of the care services they need to meet their own individual circumstances. We can see no reason why the overarching objective of care policy in respect of older people and people with dementia should not be to give them and their family carers the option of greater independence and choice in the services they receive, thus giving them greater control over their lives.

Equally, we would argue that those who wish to let services make the choices for them should be free to exercise that option. A few questions, perhaps will illustrate the point better than a lecture on theory of Consumer Directed Care.

Why should a family care who wants to attend church on Sunday be denied respite because the service doesn't operate at those hours or cannot provide the hour and a half 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 set the 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 an Indigenous person knows the person in their family and community networks who could provide respite care, why should they not be able to ask the service agency to employ them, or to broker out the service provision to a more suitable or acceptable agency?

If a person with dementia and their family carer want to plan ongoing respite on the 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 go to a day 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?

To repeat the objective of Consumer Directed Care is to give the person cared for and their family carers more choice and control over their care services by being able to choose which services they receive, who will deliver the services and when.

Arguably, the best way of maintaining a person's independence is to allow them the option to decide what services will enable them to live as independently as possible for as long as possible in the setting of their choosing.

The Evidence

The principle of CDC is embodied in care approaches in many overseas countries – and it is a principle we are taking about, not a new program. The Japanese and German health financing systems are of this kind, and give individuals the choice of receiving cash for service. A number of European countries, including the Netherlands and the United Kingdom have introduced the principle in their community care system. So too have a number of States in the USA.

I do not find it surprising, that across these different countries with varying cultures and programs, Consumer Directed Care has been shown in evaluations to provide better outcomes than those that rely on mainstream agency delivered programs. And the evidence seems to be that the quality of the care provided is at least as good. In some countries, consumers take the cash option when it is less in value from an

equivalent service on offer from an agency. That is not of course something that Alzheimer's Australia would support.

Indeed, the principle of CDC is familiar in the Australian context. It is embodied in many programs for younger people with disabilities. It was the principle that inspired the development of Community Options in the late 1980's and still does. Lets finish the job and adopt CDC more widely in aged care programs.

Many people with dementia and their family carers may be happy with the mainstream agency services that are available, but many others are not, and wish to exercise choice. This was illustrated during the seminar series that Alzheimer's Australia held last year. We invited Dr. Jane Tilly to Australia to promote discussion about overseas experience with Consumer Directed Care and its possible relevance to Australia. A discussion paper that accompanied Dr. Tilly's seminars and a report on the consultations is on the Alzheimer's Australia website.

The response of the consultations was overwhelmingly in support of trialling Consumer Directed Care. The reservations expressed, were primarily about whether consumers would want to accept all of the responsibility for managing the care, including the payment and employment of staff. The majority view was a preference for a stronger say in the determination of the services received and to have an individual budget that a service agency would administer in line with the agreed plan.

There are of course, special issues that concern people with dementia and their family carers. For people with dementia who want to exercise the right of determining their future care, advanced care planning is an option that will assist the family carer and others to make decisions when it is judged that the person concerned is no longer able to take decisions for themselves in respect of their care and living arrangements. Many of the programs that Dr. Tilly talked about overseas, provide for people with dementia to participate in CDC.

The Way Ahead

On the basis of the response from family carers, people with dementia and the service providers at the seminars last year, Alzheimer's Australia has suggested that there are three options that should be trialled in Australia.

1. Applying CDC to Australian Government Aged Care Packages

These programs – Community Aged Care Packages, Extended Aged Care at Home packages and Extended Aged Care at Home Dementia packages - are currently funded on the basis of a fixed subsidy paid to a service provider in respect of an approved person receiving a package of care. CDC would allow the care recipient to inform the care package provider of the services they would like and who they would want them delivered by limits of the care recipient's "budget". The care package provider would have the responsibility to inform the care recipient of the range of services available and the cost of each service type, once the "shape" of the necessary care package has been decided on. . The provider would then have the task of arranging these services and their payment.

This option is very close to what should constitute “good practice” in CACP and EACH provision, where the care recipient’s needs and wishes are paramount, and the task of the package provider is to facilitate the provision of the services that the client needs and wants.

The EACH Dementia guidelines have the flexibility to allow this. Indeed the model has been followed in the package negotiated between George Vassilios and Uniting Care in Victoria for his Mother who lives alone. Interestingly, George has experience of cashing out in the context of younger disabilities. In outline:

- George in effect has taken over the part of the functions of a care manager – selecting care staff, providing transport and coordinating the services provided.
- Uniting Care provides advice and a lower administrative charge as George is doing part of the case manager role.
- Uniting care holds the budget, pays the bills and employs the staff.
- There is an agreement between Uniting care and George that sets out who does what.

Some benefits of this model are that.

- It requires the service provider and the care recipient or family carer to define their roles in the joint care partnership.
- It could work well in small rural communities and for ethnic groups, where local people or people of the same cultural background could be employed.
- It would more easily enable the employment of family members, which is currently permitted under CACPs and EACH where a formal employment agreement exists.
- It avoids the complications of the care recipient or family carer having to be an employer.
- It does not necessarily require all care recipients to have the same “budget”. Currently CACP and EACH providers “pool” the individual subsidies and allocate services according to assessed need. This arrangement could continue, with the service provider determining a client “budget” after discussion with the client and an assessment of needs. It is important that the care recipient knows in advance exactly what their “budget” is, but also that this can change over time to account for changing needs.

It would be the responsibility of the package provider to ensure that the client was informed of the whole range of available services, not just those available from the package provider.

This is a vision shared between consumers and many service providers as the seminar series demonstrated. Uniting care in Victoria and Deakin University School of Nursing have secured funding for a 3 year project to develop and test a personalised and consumer/carer directed community care model that offers improved quality, responsiveness, and flexibility in support choices. And given the chance and encouragement by the Department of Health and Ageing I am sure there would be many others to lead the way.

2. Providing a cash option to users of respite care

Despite increased Government funding of respite, access to flexible quality respite care continues to be a problem for family carers. Carers complain that appropriate quality respite care is rarely available where and when they need it. This is particularly the case for people from a cultural and linguistically diverse background, or people with special care needs such as dementia, and people in rural and remote areas.

Under the National Respite for Carers Program, brokerage funds could be allocated to carers to enable them to select for themselves the respite most appropriate for them. To avoid the carer having to be responsible for handling the payments, the funds could continue to be administered through Carer Respite Centres, that would also provide information on respite services available, and the funding available.

Care recipients who wished to access respite services subsidised under HACC, the National Respite for Carers Program or the Residential Aged Care Program would still be able to do so. The budget allocated to the carer/care recipient would be solely in regard to the brokerage funds.

This would not be an option that everyone would choose. However, for those who do, there would be considerable advantages in being able to obtain respite care consistent with their cultural and social background, or special care needs.

There is a need for families to be assisted to “Imagine better” – they can identify what is wrong with existing services but often cannot locate better ones or imagine how they might create those options. This is where “technical support” can help. There is also the need for organisations who are helping to create those options to have an infrastructure to enable them to provide different options based on individuals purchasing those options (creates issues of financial viability).

The Dementia Collaborative Research Centre for Consumers, Carers and Social Research is at present writing a protocol for a systematic review to look at the evidence around the use of CDC and respite care. Once the systematic review is completed a survey and interviews with carers of people with dementia will take place. These will be built around filling in the gaps found from the systematic review and gaining feedback that would be particularly relevant to the Australian setting. This will allow a solid evidence base for the way ahead.

3. Choice between home based care and residential care

The key decision for most frail aged people or people with dementia needing care is whether, and if so, when to receive that care in their own homes or in residential care.

Put simply the Aged Care Assessment Team would assess the individual for a level of care and the subsidy it would attract. The individual and their family carer would decide with the Team where the care would most appropriately be delivered – in a care package in the home or in residential care. For a range of reasons including the health of the carer, residential care may be the best option. But for others, remaining in the home or a retirement village may be the preferred choice.

And that is often not possible now because there are so few high care aged care packages compared to residential places.

Alzheimer's Australia would favour having a trial based on existing assessment methods, to give consumers a real choice in where they receive care. Such a trial could operate in conjunction with diversified service providers who currently offer all of these forms of care. A control group could be devised from a comparable region or regions.

The thought is not new. In developing Hostel Options back in 1988 and subsequently aged care packages part of the policy underpinning was to provide subsidies at the equivalent level of residential care so that in the longer term there would be a more flexible approach to use of the aged care budget and consumers could make their own trade offs.

And again there are models overseas that may provide experience and evidence relevant to Australia. In Wisconsin, they have developed a model where the Ageing and Disability Resources Centres allocate a budget that can be used flexibly to keep the person in the community. In the United Kingdom they have also broken the link between accommodation and care.

Conclusion

A good title for reflective talk would be "Is there anything new in aged care?"

My answer would be very little – certainly if one looks at overseas as well as Australian experience. But we can certainly deliver aged care services better.

Within my memory we have talked about flexible services to meet consumer needs in different contexts for over 20 years including HACC, community options and packages. And we are still talking about how older people and their family carers who wish to do so can exercise greater choice of services and control over their lives in the delivery of care packages.

Aged care in the final analysis should be driven by values. And the value is that the consumer should have the option of controlling their own lives if that is their choice. I keep on hoping that somewhere the thought will catch the political imagination to drive a new wave of change in aged care that brings the reality of aged care into realisation of the potential.