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CONSUMER DIRECTED CARE

A REPORT ON CONSULTATIONS

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EXECUTIVE SUMMARY

Consumer Directed Care (CDC) involves giving people choice in respect of the services they receive, where they receive them, and who delivers them.

Overseas evidence indicates positive outcomes for a range of CDC models, including “cash out of services”, vouchers, and “cash and counselling” from a designated agency.

A series of seminars organised by Alzheimer’s Australia enabled Dr Jane Tilly from Alzheimer’s USA to present this evidence and suggest possible applications in the Australian context.

The seminars were well attended and audience polling indicated a high degree of support for CDC trials in Australia, with many advocating immediate introduction of CDC.

Three possible applications in Australia are proposed. These are: (1) applying CDC to Community Aged Care Packages (CACPs), Extended Aged Care in the Home (EACH) and Extended Dementia Care in the Home (EACHD) (2) applying CDC to the respite brokerage funds held by Carer Respite Centres, and (3) enabling consumers assessed as eligible for subsidised care to receive that care either at home or in residential care.

REPORT ON THE CONSULTATIONS

Consumer Directed Care (CDC) is care that enables people needing care and their carers to make choices about the delivery of appropriate services to meet their needs.

Consumer Directed Care models include a “cash out” of program funds given to the person as a straight cash benefit without strings, vouchers enabling care to be purchased from approved providers, and a model where consumers direct a care package provider on how to allocate a pre-determined package budget.

Consultations on Consumer Directed Care were held around Australia during June and July 2007. Leading the seminars was Dr Jane Tilly who is Director, Quality Care Advocacy, Alzheimer's Association, USA (based in Washington DC).

A paper by Dr Tilly and Glenn Rees, the National Executive Director of Alzheimer's Australia, entitled “Consumer-Directed Care: A Way to Empower Consumers?” was published and distributed, and is available as an issues paper on the Alzheimer's Australia website (www.alzheimers.org.au).

Consultations were held in Sydney, Melbourne (2), Brisbane, Cairns, Adelaide, Perth, Darwin, Hobart and Canberra (2), and involved service providers, consumers, government officials and academics. Attendance was high reaching 170 at the Brisbane seminar, and the involvement of so many service providers in the consultations indicates an enormous interest in the concept of providing services to meet consumers' perceived needs.

Dr Tilly's presentation was well received and she was able to respond positively to a range of questions based on overseas data on the evaluation of CDC. Dr Tilly was careful to point out the differences in the aged care systems between Australia and the USA, and stressed that Australia would have to work out its own application of CDC rather than importing an unmodified overseas model.

SUMMARY OF DISCUSSION

Support for concept of CDC

There was a very high degree of support for the concept of CDC at all seminars. The objective of giving consumers and their families choice in respect of the services they receive, by whom, and how they should be delivered, was strongly supported. While some people felt that there is a fair degree of consumer choice already, in that some care managers and case co-ordinators currently discuss planned services with consumers and their families, the majority strongly disagreed.

Almost everyone supported the idea of CDC trials or pilots with between a third and a half indicating they should be implemented immediately.

If choice is the underpinning philosophy of service provision to older people with care needs and their carers then CDC should be embraced in some form. Choice is also embodied in the Home and Community Care Program's National Standards.

Nearly all the doubts and issues raised about CDC were around the cash and voucher options where the consumer would accept all responsibility for managing the care. Others took the view that as CDC was optional, consumers who wanted to should be allowed to take these risks, and providers should not be risk averse. These issues are set out in the following.

ISSUES RAISED IN THE CONSULTATIONS FOLLOWING DR TILLY'S PRESENTATIONS

Practical difficulties with consumers employing staff

Australia's complex industrial relations scene and associated OH&S and insurance requirements were frequently raised as a barrier to CDC models where people employed their own care providers. Dr Tilly pointed out that an agent could be used to handle this side of things, while still leaving consumers able to decide who they employed.

Concerns over quality of services delivered under CDC

A general feeling was that consumers would not be able to adequately monitor the quality of the care they received, and, particularly if they employed family members, were in danger of being "ripped off". It was also suggested that Government would need to pay for training of staff or family members hired by the consumer.

Dr Tilly pointed out that in the overseas trials there was very little evidence of anyone being ripped off by family members. On the contrary, consumers felt they were much better off when services were provided by family members.

Nevertheless there was general agreement that the quality of care delivered under CDC would need to be monitored externally.

Would cash be used for services or for other things?

There was some scepticism that a cash payment in lieu of services would actually be used to purchase services. Unlike the USA Medicaid system, it would prove very difficult in Australia to prevent people who receive cash in lieu of services from also receiving subsidised services. The end result of that may well be extra cost for no extra services.

Unavailability of choice

Some people felt there was little choice available for most people needing care services, especially in rural areas, and therefore CDC would not help. Dr Tilly's reply to this was that it is in precisely in these areas where formal services are hard to obtain that employment of family members or neighbours is particularly valuable in filling gaps. For people from a culturally and linguistically diverse background, and for indigenous groups, there were likely to be attractions for some in identifying people from their own communities who could supply services – the end result might be to increase the supply of care providers.

CDC too stressful for people with dementia

Some people (including some consumers) considered CDC would be too stressful for the person needing care. In the USA examples, an agent was appointed to help people make choices and find their way through the system. This agent may be a family

member. The agent or representative acts on behalf of the person needing care. Where a “counsellor” is used, the counsellor is more akin to a case manager who consults with the beneficiary and the agent about their responsibilities under CDC and monitors the care plan and quality of services received. Dr Tilly pointed out that all the studies showing positive outcomes for CDC included people with dementia.

How can consumers know what services are available?

The “counsellor” (in US language) or case manager would inform consumers of their options, drawing on local knowledge and existing databases of services, such as those held by Carelink Centres or those available on the Department of Health and Ageing’s website.

Is CDC a cheaper option?

The answer to this is no. Unless Government discounts the cash or voucher given to the consumer, consumer directed care will not be cheaper than standard service provision. Evidence shows, however, that there may be some savings in delayed admission to residential care.

Fiscal risk for Government

Concern was expressed that consumer directed care would mean considerably more people (and their families) seeking Government assistance than at present. This would apply particularly in a cash out model (eg Carer Allowance), or where cash was paid to people eligible for care as opposed to those actually wanting care..

Dr Tilly argued that Government could still limit the number of CDC places, as they do now for CACPs and EACH. Alternatively, Government could raise the eligibility criteria to limit eligibility and contain budgetary risk.

Would Government end up paying for family care that it currently gets for nothing?

Any Government assistance in the form of cash as with the carer allowance or agency services run the risk of Government effort substituting for informal care. There is evidence to suggest that 70-80% of care is provided through informal care. The argument surely is that there should be more support to assist the carer and that it should be provided in the way that is most effective in terms of getting access to the responsive services that consumers need.

WHAT ARE THE OPTIONS FOR TRIALLING CDC IN AUSTRALIA?

1. Applying CDC to CACPs, EACH and EACHD

The most feasible option in Australia is to apply the principles of CDC to CACPs and EACH, including EACH (D). These programs are currently funded on the basis of a fixed subsidy paid in respect of an approved person receiving a package of care. Therefore, there is already a notional “budget per person” which includes both the Government subsidy and the recipient’s contribution.

The CDC proposal would be to allow the care recipient to inform the care package provider of the services they would like and who they would want them delivered by, all within the care recipient's "budget" (comprising the subsidy plus the client contribution minus a small overhead for the package provider). 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. 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 the client needs and wants.

Some features of this model include the following.

- 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 allow for 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 having to be an employer, which was a frequent objection raised during the consultations.
- 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.

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.

Not every care recipient would want to choose this option. But for those who do, the international literature indicates that better outcomes are certainly likely.

CDC could also be applied in the HACC program at the "packaged care" level in a manner similar to CACPs and EACH. The community options sub-program in HACC would particularly lend itself to CDC.

2. Respite brokerage money

Despite increasing use of respite, access to respite care continues to be a problem for carers. Carers complain that appropriate quality respite care is rarely available where and when they need it. This is particularly the case for people with a cultural and linguistically diverse background, or people with special care needs such as dementia.

Under the National Respite for Carers Program, funds are made available to Carer Respite Centres to enable respite care to be purchased for eligible people, or for existing subsidies to be "topped up" through extra payments.

Applying consumer-directed care principles to this program, brokerage funds could be allocated to carers to enable them to do their own purchasing or “topping up”. Such funds would continue to be administered through Carer Respite Centres, who would provide information on respite services available, and determine how much an individual brokerage allocation should be.

The operation of this model would require Carer Respite Centres to assess the carers’ and the care recipients’ needs in a way which would lead to a fair allocation of the brokerage funds. Care recipients would still be able to access respite services subsidised under HACC, the National Respite for Carers Program or the Residential Care Program. 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.

3. Choice between residential and home based care

The key decision for most frail aged people needing care is whether to receive that care in their own homes or in residential care. Although ACATs currently assess people’s needs, and should recommend a choice appropriate for each individual, people themselves often feel powerless in this situation and feel they are unable to exercise any real choice. This applies particularly to people who are being assessed while in hospital.

Current program arrangements require separate approval for each program (residential care, CACPs, EACH, EACHD and HACC). Each program involves a different level of subsidy to service providers. One goal of consumer directed care would be to have a single assessment of care needs. This would be associated with a level of care subsidy, and that subsidy would be allocated to the consumer, not the provider. It would mean that the consumer would be able to choose the services they want in the location they want.

This model would enable real choice for consumers between residential and home – based care, as well as allowing them to “top up” the subsidy with their own contributions.

The exercise of choice by consumers would not only be beneficial to consumers themselves, it would have the effect of introducing a degree of competition among service providers. Such competition would help raise standards of care and help restrain costs.

Both residential care and community care sectors have the flexibility to adapt to a more competitive environment. Residential care is already facing that situation with occupancy figures falling.

The option of ACATs assessing for level of care, rather than for location of care, received considerable support in the seminars. However, considerable work would

have to be carried out to develop an assessment methodology which could be applied fairly when determining the level of care subsidy across both residential and community care. The new residential care assessment instrument (the ACFI) would not be comprehensive enough for this task as it does not include many areas of community care need (eg need for home maintenance or home modification, need for delivered meals, need for day care etc). The safety of the home environment, the strength of the care recipient's support network, whether or not the care recipient's health status is stable or fluctuating, also need to be considered when agreeing to a community based package of care, as does an exit strategy for when the situation changes. However, subject to the ACFI being proven as a measure of clinical care needs, it could form the basis of a more comprehensive assessment instrument covering both residential and community care.

In the meantime, there are several ACATs who may be willing to try out this model, based on existing assessment methods, and giving consumers a real choice between residential care, CACP, EACH and EACHD. Such a trial could operate in conjunction with a service provider who currently offers all these forms of care. A control group could be devised from a comparable region or regions, with ACATs and service providers using the standard procedures.

The overseas literature indicates that affording consumers real choice in regard to their care produces better outcomes, both for the care recipient in terms of their own well-being, the well-being of their carers, and the effectiveness of the aged care system through people being able to delay their entry to residential care.

EVALUATION

The concept of CDC has been well tested in overseas studies involving large controlled trials. Applying CDC to CACPs and EACH is no more than an extension of what should be best practice.

The options put forward in respect of respite and promoting real choice between community and residential care should be subject to trials. What is needed are outcome measures applied to whatever trials are agreed upon. Such outcome measures should include take up rate, consumer and carer satisfaction, health and well-being status of recipients and carers, use of other services, and rate of admission to residential care and any incidence of adverse events.

Quality of care will also need to be monitored to ensure that the care providers, including family members, are providing the necessary level of care required,

Also necessary is some form of control or comparison group, as similar as possible to the CDC trial group, which would receive standard care.

RECOMMENDATIONS

1. Consumer Directed Care, where the consumer has the major say in determining the care they receive within the proposed budget, should be implemented as an option for consumers within the framework of the CACP and EACH programs (and perhaps in HACC).

2. A trial should be conducted enabling an option for eligible carers to use respite brokerage funds to obtain their own respite care.
3. Giving eligible people the option of a genuine choice between residential care and home based care should be trialled using ACATs to determine level of care (and level of subsidy) but not location of care.

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