Consumer Directed Care - High Dementia Packages (CDC HD)

Background
Alzheimer’s Australia has long been an advocate of Consumer Directed Care, culminating in the release of a paper Consumer-Directed Care, A way to empower consumers? in 2007. This has been driven by continued inquiry by consumers who are looking for more control and transparency in government community care packages.

In 2010 the Australian Government introduced Consumer Directed Packaged Care. The Government funds selected community aged care providers to deliver innovative service models which includes CDC packages. It is intended that these packages provide care recipients and their carers with greater control over the design and delivery of the care and services they receive. The CDC recipient is allowed 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.

Eligibility and funding
CDC packages include CDC High Care Dementia (CDC HD). This package provides services to people at home who have high level, complex care needs and also experience behaviours and symptoms associated with dementia that affect their ability to live independently.

To be eligible for a CDC Package an assessment is made by an Aged Care Assessment Team (ACAT) and approval for a CACP, EACH or EACHD is required.

CDC under this model does not include a cash system for recipients. CDC approved providers receive a daily subsidy per package to supply and coordinate care services. The provider manages the overall budget, provides monthly statements and pays the invoices for services. The level of subsidy provided for CDC High Care Dementia is $49,560 per

---

annum\(^4\). Care recipients will pay providers an agreed amount of the budget for administration fees and a small amount to cover contingencies such as emergency scenarios.

In 2010-2011 six Victorian care providers were successful in obtaining fourteen CDC HD packages\(^5\). In 2011-12 there were 8 Victorian care providers who were successful in obtaining fourteen CDC HD packages.

**Alzheimer’s Australia Vic Consumer Committee interest in CDC HD packages**

The Consumer Advisory Committee (CAC) is comprised of 15 family carers and people with a diagnosis of dementia from throughout Victoria. None were recipients of CDC HD but all were interested in further exploration of CDC. Whilst recognizing that CDC HD is relatively new, two service providers and one recipient were invited to round table discussions with the CAC in 2011. CDC was a new form of care designed to allow people more control over the design and delivery of their services. Whilst a round table discussion does not have the rigour of a formal evaluation, group discussion provides useful insights into the benefits and pitfalls of the CDC model from the perspective of both service provider and care recipient.

**Why are consumers looking for something new?**

Consumers are frustrated by lack of choice, control and transparency of funding expenditure of service providers. Personal experience and anecdotal evidence discussed by the CAC have included:

- Administration costs of service providers are so high that conventional packages leave little in terms of direct care for the person with dementia. Only 40-50% of money is spent on direct service to care recipients. One consumer calculated that she was a recipient of only 1/3 of a package, a situation she perceived as scandalous.
- Service needs are determined by the service provider and restricted to what they can offer.
- Service Providers can spend money on supplementary clients who are not funded.
- Consumers are told that there is a ‘budget’, but are not told what this is. Clients may request a financial expenses report in writing but some service providers refuse to comply.
- Consumers are told that services will increase as needs increase, and then told that the budget is not cumulative and increased need cannot be met.
- Some consumers feel that they could get more value for money if they purchased services directly.

Consumers are interested in determining what services they need, who should provide them, as well as when and where they are provided. Consumers are interested in choices which change the balance of power out of the favour of the service provider and in favour of allowing more flexibility in care.


Does CDC HD meet consumer expectations?

**Budget**
Under the Australian government CDC model recipients do not directly receive a cash payment but require a service provider to administer payments to contractors. There appears to be some very clear improvements to the equity and transparency of the budgetary process. These include:
- The client is assessed and then budget is determined in consultation with the client
- Client confidence about ‘saving for a rainy day’ through budget accrual
- An account statement is provided to the client each month
- No pooling of resources

A recipient of CDC HD described her experience with CDC compared to generic packages. Under a HACC program it felt like a funding model of ‘what you can’t have’, under a CACPs package ‘you got a little bit and then no more’ and under an EACH D package ‘you got more but had to fight for it’. CDC varied in a positive way in that it is based on a funding philosophy of ‘what you can have rather than what you can’t have’. More money is available for the care of the person with dementia and there is more choice in what to do with that money.

**Increased choice and flexibility**
Two service providers, Brotherhood of St Laurence and Baptcare participated in the roundtable discussion. They both promoted package flexibility. There was confidence in care for the future with the ability to transition out of CDC if the carer could no longer manage. Brotherhood of St Laurence gave the opportunity to gradually take on more responsibility, creating a sense of partnership. Baptcare experienced one case of a client transitioning from residential facility to home as the carer had improved health. Empowerment and partnership in choices were features of their models. Their role was seen as providing the information to the client and letting the client decide. Feedback loops were discussed and the concept of circles of support.

**Value for money**
This appears to be a winner all round. Clients tend to a nature of conservatism and accrue their entitlements.
Examples were given of the CDC client doing her research and saving package fees by finding a cleaner who was $10 per hour less expensive than agency cleaners, carers and meal providers who were less expensive but still of high quality.

**Impact on the person with dementia and their carer**
The CDC recipient felt the CDC HD package was very beneficial for the person with dementia. The recipient believed her husband was calmer living in his own home.

Anxiety about contingency plans in the event that the family carer became unwell continued under this package. The CDC recipient was not a client of Brotherhood of St Laurence or Baptcare and was not familiar with a transition system in the event that she became unwell.

The CDC recipient was committed to the CDC package concept as well as the provision of excellent care for her husband. This created a huge work load and was exacerbated by the inexperience of her service provider. She was also deterred by having to pay $100 per hour for a Case Manager. This lead to a need for committing time to completing a myriad of care plans including meal plans, weekly service plans, day plans and medication plans. Interpreting
budget and choosing how to spend funds added to the emotional burden. This was not sustainable in the long term particularly as the person with dementia deteriorated.

Despite challenges, the CDC HD recipient continues to be a proponent of the CDC model; its value, flexibility, choice and transparency were superior to generic packages. Additional purchase of case management from a service provider may assist when the caring role becomes onerous.

**Demand for CDC packages**

CDC HD packages will attract people who have good organizational and budgeting skills. Skills and attributes are required for CDC HD. At a minimum these include:

- A good level of insight into needs of the person with dementia
- A good understanding of financial statements
- Confidence to contact the provider on a needs basis.

There is little doubt that not everyone wants the same level of responsibility and control over budgets.

It was the experience of both Baptcare and the Brotherhood of St Laurence that only a small percentage of existing clients were willing to change over to CDC packages. It is thought that up to 10% of existing community care package clients would like to have CDC. For example Baptcare, Northern Region wrote to 200 clients and only 2 accepted indicating a 1% uptake. There are a number of factors for this but may also include a tendency to stick with the status quo believing that if it ‘aint broke why fix it’? Some were attached to their current case manager and some felt they would change if they were a bit younger in age. Although only small numbers make it difficult to generalize, it appears that at this stage there seems to be higher uptake by people from different cultural background and by those clients whose packages are managed by their children. The emotional and physical burden of caring may be prohibitive as well as lack of computer literacy amongst older carers.

**Is it the way of the future? What improvements are required?**

CDC is still fairly new and some service providers are still learning about this model.

The number of CDC packages are few, with very limited availability. For many people it is not an available option even if they are interested. It is also not well understood or promoted.

CDC has many good points but will not appeal to everyone and one size does not fit all. Whilst CDC HD appears dementia friendly it appears to still be evolving to become more user friendly. Guidance material, mentoring and coaching models for the recipient is recommended.

As clientele change in the future, case management of ‘generic’ packages will need to change as well to reflect CDC practices. Good quality case management in generic packages should be able to support some elements of CDC.

If the client needs regular case management then these require ‘purchase’ and would make a CDC package more questionable as an option. Done properly CDC HD requires a large amount of extra work from the family carer. They must be physically and mentally up to the challenge. This may make CDC appealing to the children of the person with dementia,
particularly demonstrated by the uptake of CDC HD by children of people from a CALD background.

As diagnosis of dementia improves, CDC packages need to be offered promptly before carers become burnt out and unable to consider this as an option. The CDC HD recipient involved in the round table discussion believes CDC HD is best targeted at people in the early to mid stages of dementia. In the latter deteriorating stages it is too challenging physically and mentally to be caring for someone whilst taking on a very serious management role. In some instances this may be able to be divided up by families but often is not an option.

A cash-out system has fewer advocates. This model would need significant safeguards with a large requirement for guidance and mentoring.

An official evaluation of CDC by KPMG was released in 2012 and also informs the CDC discussion.

Alzheimer’s Australia Vic Consumer Advisory Committee round table discussion can conclude that if the CDC client does their research, and ‘shops around’ for services they can receive good value, flexible and good quality care, with greater choice. These are all reasons for demand for CDC in the first place.

**Acknowledgements**
Alzheimer’s Australia Vic sincerely thanks the contributors to the CDC round table discussions:
Alzheimer’s Australia Vic Consumer Advisory Committee
Anne Fairhall, carer of a person with dementia and recipient of CDC HD package
Anna Gullaaci (Care Manager, Northern Community Packages, Baptcare)
Brad Cooper (Regional Manager - North East Victoria & Tasmania Baptcare),
Lisa Rollinson (Senior Manager. Community & Aged Care. Brotherhood of St. Laurence).

**For further information please contact**
Dianne Biermann, Policy Officer, Alzheimer’s Australia Vic

March 2012