

Is Consumer Directed Care a direction for Australia?

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“Consumer directed care” is such an empowering term, how could we question whether it is a direction that Australia should take? But as the term is not well known in Australia, we need to establish just what it means before we head in another new direction, and indeed ask whether we have gone there before under another signpost.

These questions were addressed in a session on Consumer Directed Care (CDC) at the International Association of Gerontology World Congress held in Vancouver in mid 2001, and papers presented at that session provided the starting point for this paper. Fuller accounts of the development and current status of consumer direction in the US by two of the speakers at the IAG session, Robyn Stone and Jane Tilly, and others, can be found in the references listed at the end of this paper. In particular, the special issue of the journal *Generations* on Consumer Direction in Long Term Care, published in Fall 2000, gave a wide-ranging account of the state of play at that time and emerging directions of development.

The aims of this paper are threefold:

1. to review the meaning and development of CDC in overseas programs, and especially to draw attention to the policy and social cultures in which different initiatives have been taken;
2. to consider factors in the Australian policy and social context that may affect the transferability of international experience to the local scene; and
3. to analyse the extent to which different elements of CDC are already found in Australia’s aged care and disability programs and to canvass some options for further development of CDC.

It has not been the aim of this paper to make a comprehensive review of all the models and meanings of CDC in different countries. That task has been addressed by others, and in drawing on those accounts, the focus here has been on common features and the relevance of different models to the Australian scene. There is an unavoidable loss of detail, and those seeking information on particular programs are directed to the references and web sites listed below.

This paper is also very much a first account of some of the issues facing CDC in Australia. The aim has been to set the scene and canvass a wide range of issues, and giving more in-depth accounts of emerging models remains a task for future research. The initiative taken by Alzheimer’s Australia in commissioning this paper provides a lead to others, and it is hoped that the paper will prompt further discussion and indeed experimentation in future policy and program development.

Defining Consumer Direction

Three points need to be made in attempting to define consumer directed care, and to distinguish it from standard, agency directed care.

1. Provision of cash benefits to enable clients to purchase care services is generally taken to be the distinguishing feature of CDC. However, not all programs that adopt consumer direction provide direct cash benefits, and among those that do, some restrict the use of benefits to paying for approved care services and others are unrestricted. Provisions for using cash benefits to pay family members also vary: it may be permitted as an approved service, or left to the discretion of the recipient of unrestricted benefits, and while some programs allow payment of any relative, others exclude payments to spouses. Unlike the Australian Carer Allowance and Carer Payment, which are paid directly to the family carer, payments under CDC are made to the individual who is in need of support who in turn pays the family carers.

2. There is no single model of consumer directed care, and CDC rarely stands alone but is commonly one component of a wider service program. Conceptually, CDC is most positively defined as a means of enhancing client autonomy by giving the client control over the care they are to receive from paid providers, including paid family members. It thus represents the opposite of agency directed care which is controlled by the service provider. The scope of consumer direction as practiced in different programs varies widely.

At its narrowest, CDC means that the client, and their carers where present, have a greater say in the planning of care to be provided by agencies and in the delivery of services than is usually the case. The starting point for CDC is thus variable, depending on the extent to which clients normally have a say in standard community care programs. Further, while anecdotes of agencies being very rigid in applying “the rules” as to what care workers can and cannot do are widespread, it is less clear whether they reflect atypical cases, arise in particular circumstances faced by some groups of clients, or occur commonly for many care recipients. A better understanding of the difference between the say that consumers currently have and what they would like to have is needed if CDC is to achieve real change in this area.

Interest in consumer directed care appears to increase with increasing levels of support from formal services and closer personal interaction with care workers. When services provide only routine home help for a few hours a week, consumer may be involved in decisions about timing of worker visits and the tasks they are to carry out, but the scope for consumer decisions expands considerably where help is provided more frequently, for longer periods, and involves closer inter-personal contact between the client and the care worker, as occurs in personal care and in-home respite, and where family members are also involved in negotiating the balance of formal and informal care. The focus of this discussion is on consumer direction of personal care services for frail older people, but for many families with a child with a disability and for young adults, the scope for consumer direction may extend to a much wider range of education, employment and recreation activities, and the potential for increased control over decision making about support services increases

commensurately. In summary, the more the individual has to rely on others to maintain their daily activities and to exercise choices of day to day living, the more is at stake for consumer direction.

At its fullest, CDC means that the client is not only involved in decisions about the kinds of services they see as most appropriate to their needs, and controlling when, how and by whom care is to be delivered, but they also take on responsibility for hiring and firing care workers, and for training and paying them, and managing day to day delivery of care.

Between the narrowest and fullest scope of CDC, there is a great range of possibilities in the design of programs. Table 1 summarises the variations found in just two of eight US programs reviewed by Tilly and Wiener (2001). In these two states, Wisconsin and California, CDC operates through county levels agencies, adding another layer of variation. Wisconsin's Community Options Program has been selected because it should be familiar as one of the international models that contributed much to the model for Australia's Community Options and Community Aged Care Packages; it is a highly structured program and operates on a brokerage model rather than direct cash payments. At the other end of the spectrum is the Consumer Directed option in California's In Home Supportive Services Program; the CD options that allows considerably greater consumer direction across a range of decisions is dominant in California, with agency directed programs running alongside CDC programs in only around a dozen counties in the state.

3. Not all programs that provide cash benefits go under the name of consumer directed care. A variety of cash benefits in Austria, Germany, the Netherlands, Israel, and Japan allow for a high level of consumer direction, with few constraints on how the funds are spent, but do not carry the CDC label. These payments have developed through universal or near universal social insurance schemes for long term care. International reviews of these programs show that provision of cash benefits is not synonymous with CDC as practiced in the US, with cash payments mainly provided as an option within a wider program rather than through specifically designed CDC programs that have been the more typical model in the US.

Cash options for people with disabilities were pioneered in the UK from the early 1980s through the Independent Living Fund, and since 1997, Local Authorities have been required to make a cash options available to younger people with disabilities; this requirement was extended to older people in 2000. A CDC pilot program in France in the early 1990s has recently become a permanent program that provides a means-tested cash allowance for persons with disabilities, aimed at helping with purchase of services.) The UK and French initiatives have both increased opportunities for consumer direction, but in the case of the UK especially, the expansion of of cash benefits as an option in statutory services was associated with wider policy agendas concerning diversification of service provision coming on top of the underlying drive for CDC, in the wake of the Royle Commission on Long Term Care. r se.

And as discussed below, the predecessor to the Carer Allowance, the Domiciliary Nursing Care Benefit, can be seen as a pioneer of consumer direction in Australia, although never perhaps recognized as such then or now.

Table 1: Variations in Consumer Directed Care Programs

| Feature of Program | California In-home Supportive Services Program (IHSSP) | Wisconsin Community Options Program (COPs), Community Options Program Waiver and Community Integration Program |
|---|---|--|
| Commenced | 1978 | 1982 |
| Admin. responsibility | Counties | Counties |
| Eligibility: Functional | Disability expected to last 1+ yrs, and need for services Financial: US Medicaid rules | Severe medical problems; substantial medical problems with no informal support; chronic mental impairment; discharge from nursing home |
| Eligibility: Financial | US Medicaid rules apply | Asset test of \$65,000 and Medicaid rules |
| Range of services | Assistance with ADL and IADL | Any services the client needs |
| Type of benefit | Authorized hours of service; 283 hrs monthly for most highly disabled | No specified limits |
| Cash payments | Clients have the option of 1. taking cash payments and full responsibility for workers, 2. having finances managed by the agency 3. receiving services from the agency with little consumer direction. | No, individual budgets managed by agency |
| Able to hire a relative | Yes, and majority of workers are family members. | Yes, except spouse |
| Counseling and case management assistance | Little or none from program. Training required for medically related tasks only, and training can be provided by nurses or consumers | Workers must receive training or demonstrate competence in six areas, including personal hygiene, beneficiary conditions and consumer direction. Consumers may train workers. |
| Worker pay rates and benefits | Minimum wages No benefits (such as pension contributions, insurance) | US \$6.00 to \$15.00 per hour. Benefits vary by county. |
| Quality assurance | Annual home visits from county agency staff; counties must operate complaints hotline and respond within 24 hours Some counties have more extensive QA systems | Case managers must have monthly contact with all clients; in addition, a private organization does a paper review of Medicaid waiver beneficiaries and makes visits to a sample. Outcome measures being developed. |

Source: These two examples are selected from details of programs in 7 states reported by Benjamin (2001) and Tilly & Wiener (2001)

How far has consumer direction spread?

The US: Uneven outcomes over 30 years

The origins of current interest in CDC can be traced to the activist disability movement as an off-shoot of the wider consumer movement in the US. Initiated by younger people with disabilities, CDC was at first adopted only in individual service provider agencies and piecemeal programs, but over the last decade it has been taken up more widely by federal and state governments and agencies such as the Centers for Medicare and Medicaid Services (CMS, formerly known as the Health Care Financing Administration) seeking to promote change in established service cultures. The application of CDC in aged care is the most recent development, and it appears that the impetus has come as much from policy makers transferring their experience from the disability field as from individual older people, their carers or their representative groups.

While CDC began in California and Washington State in the 1970s, and has become widespread in California in particular, its spread has been uneven over time and across states, and remains far short of a universal care option today. The number of programs increased through the 1990s, stimulated in part by the move by CMS to approve Medicaid waivers to allow Medicaid funds that would otherwise have purchased personal care services to be paid out as a monthly cash allowance. To establish the extent of CDC programs, investigate aspects of program design and operation, and promote consumer direction for older people, the Robert Wood Johnson Foundation in conjunction with US Department of Health and Human Services initiated the Cash and Counseling Demonstration and Evaluation Project in 1996, funding for nine service demonstrations and three research studies spread widely across the US. Reports on principles, planning and progress with implementation and early outcomes from the Project are now becoming available, and many can be accessed through the National Program Office at www.inform.umd.edu/AGING.

A report of national surveys carried out as part of this project found that even 30 years on, availability and interest in CDC remains highly variable (Velgouse & Dize). Two thirds of the relevant agencies surveyed responded to national surveys conducted in 1996 and 1999, and the total number of programs identified increased from 103 to 185. While consumer directed programs were offered by almost four out of five state departments dealing with mental retardation and developmental delay, they were offered by one in two of all the departments responsible for ageing.

Take up of consumer direction on the part of clients is difficult to assess in the US as it depends on a CDC program being available locally, the target population served, and the eligibility conditions of the particular program. Some programs, such as the Californian IHSS, serve very large client populations, but others are much smaller and serve more selective client groups. Take up is also affected by the eligibility conditions of different programs, which as well as covering functioning and need for personal care, usually include financial conditions linked to US Medicaid eligibility. As a result, most beneficiaries are individuals with low incomes, and appeal of cash benefits to these individuals and their

families may be greater than among middle and higher income groups as they face different trade-offs between having more cash vis-à-vis spending more time providing care or arranging purchase of care services.

Funding and administrative complexities appear to be a factor limiting the spread of CDC, both on the part of agencies and clients. Each program in the US draws on different mixes of federal Medicaid funding, state funding and county funding, and have different funding and contracting arrangements. The demands placed on clients are greatest when the client assumes the role of the employer of a care worker, and becomes responsible for paying the salary, insurance and other taxes and so on. In canvassing ways of reducing these burdens by relieving clients of these management functions, models such as “vendor fiscal intermediaries” have been proposed (Flanagan and Green, 2000), but as the name implies, may not be a simple solution.

Recent and rapid provision of cash benefits in other countries

A starting point for tracking the spread of payments for care in lieu of services is provided by the reports on 13 European countries, Israel, the US and Canada, compiled by Evers, Pijl and Ungerson in 1994. While they found a great diversity of arrangements and mixes of support from public, private, voluntary and household sources, direct payments for care fell into three broad groups of attendant allowances paid to the care recipient, payments to carers, and payments to volunteers. The editors note that developments to that time had been incremental, except in Austria, and that they have come about in the context of wider social policy debates about the involvement of clients and carers in decision-making about care, and about the future of labor markets, work and income, and the changing nature of families. In the European countries, consumer advocacy and disability movements have exerted their influence in the context of wider reforms of national social insurance funding arrangements, whereas in the US, their role has been more focused on the promotion of CDC as an option within very diverse service delivery and funding systems mainly at state level.

Although payments for care were seen to have become a permanent part of welfare systems across Europe by the early 1990s, subsequent developments have seen some more radical shifts than were then envisaged. The most significant and unexpected developments have perhaps been in Germany, which was not included in the 1994 compilation. Further, while Britain experienced rapid growth in payment of attendant allowance through the late 1980s and early 1990s, much of that funding was, *de facto*, used to pay for residential care. There was then little if any hint that cash alternatives to social care would be introduced in the next few years. In Japan, cash payment were included in the long term care insurance scheme as much by default as by design, to address concerns that the service system in some local areas lacked the capacity to expand to meet the increased demand that would be stimulated by the new scheme. Feminist groups were strongly opposed to the cash option on the grounds that it would reinforce the traditional roles that women were seeking to escape.

While the provision of cash benefits in a number of European countries, Israel and Japan all share some features of CDC, they have generally developed in conjunction with the implementation of universal social insurance schemes for long term care or other reforms to national programs. The national coverage of programs in these countries has seen cash

benefits become much more widely and more quickly available than has been is the case in the US. This outcome owes much to the wider social policy frameworks in which they have developed, with cash benefits being one component of universal or near universal programs providing long term care, usually covering residential and community services. While consumer advocacy has had an influence in the development of these program, access to cash benefits has not been restricted by the inclination or otherwise of different agencies to engage in demonstration projects offering CDC or cash payments.

Experience in the UK however shows that universal availability does not necessarily mean a high level of take up of a cash option. Glendinning (2002) reports that as of late 2002, only some older people nationally had chosen the cash payment and they accounted for around 12% of the total of around 4,000 clients nationally. The restrictions placed on the UK scheme by way of excluding payment of relatives and purchase of statutory services, and a relatively weaker consumer voice among older people, have no doubt contributed to this low take-up. Tilly also reports that a reasons for slow takeup include resistance of some local social service authorities and lack of knowledge or understanding of Direct Payments on the part of case managers and users of care. These outcomes testify to the strong continuing role of providers as intermediaries and that if cash benefits are to achieve the goals of CDC, these goals have to be embraced and promoted by provider agencies.

One aim of providing cash benefits in the UK appears to have been to stimulate the “care market” by way of provision of services by commercial agencies as an alternative to statutory providers, notably Local Government. This consideration was also a factor in Austria. Given the different policy contexts in which cash payments have come into being in different countries, it is hardly surprising that there is great diversity. Reviews of programs across these countries (Tilly & Wiener; Brodsky, J., Habib, J. & Mizrahi, WHO) have reported a wide range of approaches in all elements of program design including:

- functional and financial eligibility criteria,
- the number of eligible beneficiaries and the proportions opting for cash benefits,
- the range of services covered, with most limited to personal assistance,
- benefit amounts and levels of payments,
- options for combining varying levels of cash and services vs. an all-or-nothing choices;
- the balance of funding from general taxation and long term care insurance premiums;
- whether relatives can be hired and paid; and
- provisions for quality assurance.

The different approaches and outcomes in the US compared to the European and other countries present many choices in looking to further CDC in Australia. But before deciding whether to proceed through a series of specifically designed demonstration projects, or in a single step such as introducing a cash option in HACC, we need to ask how far CDC would be a new direction.

A new direction for Australia or back to the future?

Australia's early experience with the Domiciliary Nursing Care Benefit, now the Carer Allowance, can be seen as pioneering a cash benefit, and so provides a further example of the variety of approaches to CDC.

In hindsight, the conditions under which the DNCB was introduced seem very generous, yet it was never widely taken up or gained strong support from older people, their families, service providers or government. Some of the many lessons that can be learned from this experience are:

- **Relativity to residential care:** The DNCB was worth 56% of the nursing home benefit in 1974, but was not indexed and the relativity of the Carer Allowance today is around 10%. While the Carer Allowance is now indexed to the CPI, it is not linked to residential care benefits. Any move to restore a link to residential care costs would need to consider both discounting that is commonly in the order of 50% for cash benefits rather than in-kind services, and how receipt of a cash benefit would affect access to subsidised services. Simply paying a cash benefit that can only be used to purchase approved services and clawing it back in fees achieves little by way of consumer direction.
- **Take up is not automatic:** There needs to be a concerted and continuing effort to promote take up among those eligible. At the time of the introduction of the DNCB, staff of home nursing services expressed a number of grounds for their reluctance to promote it, ranging from not being funded to carry out the necessary assessments, to concerns that families would waste the cash. In contrast, the number of recipients doubled between 1990 and 1999 following a number of promotion efforts through Aged Care Assessment Teams and other agencies.
- **Cash payments complement rather than substitute for other community services;** if for example respite care is widely available and affordable, the need for cash payments to enable carers to purchase respite may be less relevant.
- **There is continuing ambivalence towards cash payment on the part of family caregivers and policy makers,** and even the staunchest advocates recognise that providing cash might not stimulate market based provision of needed services. The extent to which US programs involve supervision through counselling and support to the client indicate that client-worker relations are far from unconstrained, as do options for having the client paying a small fee to have a "certified fiscal agent" manage the funds.

How does consumer direction fit in with Australia's care culture?

Australia presents a very different socio-cultural setting for the introduction of CDC for older people compared to the US on the one hand and the UK and continental Europe on the other. Most specifically, even though the consumer movement has gathered strength in recent years, it is not as culturally embedded or as strong in Australia as in the US. Among the reasons

are that many of the supports that older consumers have had to lobby hard for in the US, and with only varying degrees of success, are readily available in Australia; the Pharmaceutical Benefits Scheme is a case in point. The relationship between government and consumer bodies is also far less adversarial in Australia, where organizations such as the Alzheimer's Association and Carer Australia are given standing in a wide range of consultative forums and receive considerable public funding. In the US, it is much more likely that such close relationships would be seen as compromising the independence of consumer representatives.

Three wider cultural contexts are also very relevant. First, Australians historically have been reluctant to either be, or to engage domestic help. As Kingston (1975) makes clear in her account of women and work in colonial Australia, "My wife, my daughter and poor Mary Ann", the ready demand for workers in all fields of economic activity made it difficult to find servants; the long, but defined hours and regulated conditions of factory work were preferred to the unlimited hours and idiosyncratic conditions of domestic work. The very absence of a servant class was one factor limiting the rise of a middle class, defined at the time in Britain as those who employed a servant. The employment of domestic workers today is very much the preserve of dual and high income households. Neither the form of demand for or supply of these services can be taken as indicating that the conditions exist for creating a care market by providing cash benefits that recipients can use to buy their preferred services.

Second, and in part related to the general historical shortages of labor, the Australian workforce has been much more organized and unionized, and workers less prepared to work for non-standard wages and conditions than in most other countries. Older people are especially more likely to identify themselves as workers rather than employers of labor and few, especially older women, will have had any experience as an employer. A key characteristic of CDC that is emphasised in the US is that the client is empowered to "hire and fire" but this power may have far less appeal to older Australians and even their younger family carers. Employee organisations are also likely to resist any moves to see a group of low paid "workers" with few protections develop under the guise of CDC.

These labor market factors have changed considerably, but not perhaps to the point where all older people want to enter into enterprise bargaining to negotiate an individual workplace agreement with paid care staff, or to see their home become a workplace subject to occupational health and safety regulation. More immediately, the difficulties that established service providers are facing in recruiting workers are hardly likely to be less for individual clients seeking to hire carers. There is considerable anecdotal evidence of the difficulties of finding and keeping carers in disability programs that provide for attendant care. Australia's income support system is also more comprehensive than in the US, so disabled members of low income families may be under less pressure to seek cash benefits to pay other family members a very low hourly rate for caregiving work.

The third aspect of cultural context is the fit between CDC and prevailing political ideologies. Cast as a means of promoting individual responsibility and supporting the family, and a form of privatization of welfare that by-passes publicly funded service agencies, CDC might readily be seen to be in line with the social policies of the present federal government. As the federal government pays cash benefits, payment of cash benefits

for CDC through Centrelink would involve a change in the responsibilities of the levels of government. State governments that are responsible for delivery of service programs are likely to be reluctant to see any part of joint funding revert to the Commonwealth, or even to accept cash payments through service providers if the consequence was any real or perceived reduction in levels of direct service provision. In local communities. Many other proposals for reform in community care have run aground while trying to navigate the shoals of intergovernmental relations, and the sailing may be no smoother for CDC.

Elements of Consumer Direction in current programs and options for further development

Elements of CDC can already be found in three areas of community care in Australia. In addition to the Carer Allowance, support for Attendant Care under the Commonwealth State Disability Agreement gives a high degree of client control, and different compensation arrangements give beneficiaries varying degrees of control over the payments they receive; some have almost total control over very large lump sums. A basic analysis of the scope of CDC that can be discerned in these different schemes is set out in Table 2, and in turn provides the basis for considering the options for further development set out in Table 3.

This analysis shows that we have more experience with CDC than perhaps we realise, and at least three proposals can be put forward for ways of exploring ways ahead. These proposals demonstrate varying balances between cash benefits *per se* as a universal option for all recipients of community care services, and models of CDC involving case management, including management of cash benefits, limited to clients with complex needs and using multiple services. These proposals and the examples of existing programs given here are illustrative only and do not represent the full range of initiatives that are currently underway, being planned or that could be envisaged. Identifying and developing a systematic account of the experiments that are already underway and planned is a necessary step for informing further development, but lies beyond the scope of the present exercise.

Cash-in-hand

The most widespread form of consumer direction at present is through the Carer Allowance. In 2000, some 200,000 people receive the CA, more than double the number of recipients a decade earlier. As many of those who receive the CA care for a person who is receiving other services, the CA is usefully seen as part of the full array of HACC and disability services. While there are no restrictions on how the CA can be spent, consumer choice is limited by the amount of the benefit, currently \$43.85 a week. The CA is not means tested, but to the extent that means tested fees apply to other services that are received, the CA may go to paying these fees.

As the CA is commonly paid alongside the delivery of care services, it suggests the simplest option for extending consumer direction, namely offering all HACC clients the option of cash in lieu of services, along the lines of the UK approach. As the great majority of HACC clients receive only very limited services, the amounts of cash payments would be small; any

restrictions on use of the payment would not be practicable as the cost of supervision would be excessive.

An indication of likely interest in a cash in hand option might be gained by surveying CA recipients who care for people using other services as they will have had experience of a mix of cash benefits and services and so know the pluses and minuses of both. The experience with implementing the Veterans' Home Care Program also has some relevance to a possible experiment with a cash-in-hand option. It demonstrated that older clients could and indeed did make a choice between remaining with their existing provider or switching to a new provider. The choices presented may have been more apparent than real in many local areas where the major existing provider won the contract to deliver VHC services, but this was not always the case. Given that veterans are a client group who have long identified with services provided by the Department of Veterans' Affairs, it might have been expected that their allegiances would lead them to choose the VHC option, but outcomes varied. Generally it appears that the majority stayed with their existing provider, or made a "seamless transition" where the VHC provider was the existing provider. Older clients might be expected to be similarly conservative in making choices between known services and a cash-in-hand option. The importance of staying with a known provider, and keeping the same care worker, suggests that the success of any experiment with a cash-in-hand option, or indeed with the mixed models outlined below, would be enhanced if developed through existing providers rather than separate channels.

An Australian experiment paralleling the UK initiative could be initiated directly conducted through the HACC program, with a number of possible components. A first step could be linked to the Carer Allowance, on the grounds that recipients of the CA have experience with a cash benefit for care. A number of questions that would need to be addressed in planning such an experiment can be identified.

First, it would be useful to investigate how the CA is spent and whether any additional cash payment would be used to "pay" family carers, to contribute to general household income, or to pay for more HACC services, or purchase private services. HACC clients whose carers received the CA could be offered the option of a cash alternative, with no restrictions on how it was spent, and with an option of continuing to purchasing HACC services or returning to services at any time. WI & OR in the US, as well as the UK and the Netherlands offer the option to users of mainstream services. The offer is not dependent upon the presence of a carer. Such an experiment would need the cooperation of major agencies such as the Home Care Service of NSW or Local Government in Victoria, but could be trialled in selected regions in the first instance. Two of the many questions for designing a cash-in-hand experiment are:

1. What is the range of services that can be cashed out, and particularly is nursing in or out of scope? The overseas programs generally cover only "social care" services of home help, personal care, day care etc, although the boundaries with nursing and other health care services that can be delivered in the home are blurred.

2. Is the level of cash payment to be set individually, on the basis of actual services used by each client, on the basis of services assessed as needed, whether received or not, or at flat rates for clients at different levels of dependency and service use? Again, international practice varies, but the social insurance schemes generally offer three or five broad bands of benefits. Developing a client classification would be a prerequisite to a banded approach in Australia.

As a payment to the carer, the CA does not constitute proper CDC, which rather requires that the cash payment goes directly to the person who would otherwise receive services. The second question for any experiment is then whether future cash payments should remain in the carer's hands, as with the CA, or be put in the hands of the person receiving direct care services. There is a clear difference between the design of a cash payment intended to increase CDC as a means of empowering clients themselves, and making a cash payment in recognition of the carer's role. The latter kinds of payments emphasise the interpersonal basis of caregiving relationships, whereas in giving control over funding to the person with disabilities who is receiving services, CDC creates more of a contracted employer-employee relationship between the individual and their carers, whether family members or non-related persons. These differences were central to the case put by Independent Living advocates in the UK who successfully argued that cash payments should remain in the hands of the person who was receiving services and that carers, when they received cash, should use it for services that support their caring efforts rather than for discretionary spending. This debate demonstrates clearly that cash benefits and CDC are not synonymous.

The third area in which a number of questions arise are with regard to overall levels of funding and the impact of a cash option on service availability. A number of caveats need to be flagged. A cash-in-hand option does not mean that funding would automatically become available to cover all who were eligible, or cover all needed services, and so make up for previous shortfalls in levels of service provision. Rather than increasing the size of the HACC pie, a cash-in-hand option might simply see the pie sliced in a different way, with a proportionate reduction in the size of the slices available for funding direct services. More funding for community care requires an increased budget, whether used to increase the CA or to add a cash-in-hand option over and above the existing funding of services. Increasing the CA would not increase consumer direction in its strictest sense as the CA is paid to carers rather than clients. Whether cash-in-hand, as an alternative or a supplement to services, translates into a larger volume of services also depends on how easily cash can be turned into services at a lower cost, how far the cash is used to pay family members for support they have already been providing, and whether a discount is to apply, as discussed below.

A cash-in-hand experiment would be a big and bold step towards CDC care in that it would be available to large numbers of clients and involve macro-level reform. But paradoxically, it is not as high risk a venture as it might seem as the decision to take the cash would lie entirely with the client and their carers, and an effective safety net would be provided by the possibility of returning to the standard services.

Mixed models

The CA also provides a cash component for those receiving a case managed package of one kind or another, provided that they have an eligible carer, and the basic cash-in-hand option outlined above could be applied to those receiving higher cost care packages. The scope for consumer direction increases in care packages as there are more areas for negotiation in arranging the mix of services that best meet the client's needs. To date, case managers have acted as brokers, but there seem no reasons why this function could not be handed over to clients who are willing and able to take it on themselves or jointly with a family carer.

Mixed models for CDC may be needed to cover different arrangements depending on whether the client opts to purchase services from different agencies, to engage a family member as their care worker, or to employ another person. In the two former case, payment of the funds to the client to use as those choose, including paying a relative, would obviate the administrative work associated with the client becoming an employer, but would leave the relative without the protections that other workers would have. For clients who prefer to engage a non-relative worker, but who are reluctant to take on or experience difficulties in carrying out the employer role, the case manager or another provider agency could carry out this role (of the vendor fiscal intermediary).

The scope of CDC increases again when the package of services includes attendant care. Some attendant care schemes provide a cash payment that the client uses to employ an care worker, while in others, the agency manages the employment of attendant care workers. The extent to which different arrangements apply is not known, and establishing the range of provisions and outcomes with different models would be an important contribution to further development of CDC.

The development of models offering various mixes of cash and services, and different levels of case management over budgets, is already beginning with small scale experiments in which cash benefits are offered to selected clients within a wider case management program. Case managers are continuing to have a considerable counseling and oversighting roles as both they and clients are feeling their way. The Uniting Church Community Options Program in the eastern Metropolitan Melbourne is planning such an initiative for 15 younger clients. This model appears to be similar to the Attendant Care Scheme that operates in Victoria as part of the Commonwealth State Disability Agreement.

While seeming to be a radical move, single agency experiments with mixed models of CDC incorporating cash payments are rather small and timid steps towards consumer direction. Unless taken up on a system wide basis, and not at the discretion of provider agencies, they are likely to cover only small numbers of highly selected clients. Case managers are likely to retain a substantial influence over consumer choices, and micro-level administrative reforms might well increase rather than decrease the complexity, and hence cost, of multiple transactions that are the cause of much present frustration. The main rationale for pursuing such experiments are that the benefits to the clients involved and their carers may be considerable. As well as being worthwhile in their own right, these experiments can test the climate for wider system change. Offering full scale cashing out of CACPs and other

packages would require a significant relinquishing of control on the part of case managers, and an important factor in promoting take up would be to allow all major HACC, CACP and disability service providers to offer such mixed models to clients at a package level of care rather than requiring clients to transfer to a separate agency.

Cashing out CACPs or EACH services would not per se add to the total quantum of services. To date, resources for package services have been in lieu of, not in addition to residential care services. Increasing the number of packages providing services and/or cash in lieu of existing or future residential care places would further change the balance of care, and bring a marginal shift in control of services, but it would not add to the total quantum of resources available to provide care across the older population in need of support. The only means to securing more public resources is an additional budget allocation to aged care.

Integrating services and cash payments in compensation schemes

While somewhat outside the scope of community care for older people, some brief comments can be made on possible lessons to be learned from compensation schemes that provide varying mixes of cash payments and services to individuals who are catastrophically injured through workplace or motor vehicle accidents or medical misadventure. Concerns that relatively small amounts of cash benefits likely to be paid in CDC might be misspent are put into perspective when it is recognised that in some of these cases, very large compensation payments, sometimes in the millions of dollars, are paid with few if any conditions on how they can be spent and with no surety that they are managed effectively to cover the cost of life long care and income support that they are implicitly intended to provide.

There are some important differences between workplace and motor vehicle insurance arrangements from state to state in Australia, but there is an increasingly strong focus on rehabilitation and return to work. This outcome is achieved for the majority of injured individuals, but there is a small residual group for whom these outcomes are not realised and whose on-going management is complex and very costly.

A report on a pilot project of a Coordinated Care Program within the Victorian WorkCover Authority provides some insights into the benefits of the program and barriers encountered in its development (Summers, Ellison & Dalton, 2000). The Program aimed to address the needs of just over 100 clients, who were either those with acquired brain injury or claimants experiencing difficulties with pain management, including perceived high levels of use of legal and illegal drugs. Both informal and formal coordinated care arrangements were offered, with differing degrees of oversight and enforcement by case managers. The evaluation found that the program appeared to generate positive outcomes for most claimants, and these gains can be linked to elements of CDC evident in the Program; claimants and their families became much more involved in developing their on-going care plans, and the increased ownership of the care plan achieved benefits in quality of life and more satisfaction with support services. Increased independence was in some cases linked to a reduced reliance of formal services.

These gains were not easily or automatic to achieve, for claimants and their families, for the WorkCover Authority, or for the many stakeholders involved, including third party insurers, case managers and medical practitioners supervising care plans, and authorised service providers, notwithstanding a strong commitment to the Program on the part of all concerned. While the report notes many limitations to the evaluation, it provides an excellent case study of the process of change that is required on the part of funding authorities and service providers to realise sustained benefits for clients.

The reluctance of insurers to take on long term case management roles has been one of the reasons for the preference for making lump sum settlements rather than continuing payments to cover income support and care. This situation is set to change however with the introduction of Structured Settlements in Australia in late 2002. Structured Settlements make it possible for injured individuals to choose, or for courts to order, that settlements be paid as pensions that will provide income support and cover the care needs of the individual for the rest of their life. The development of Structured Settlements has been a long and complicated process, requiring changes to many areas of State and Commonwealth legislation including removal of the disadvantageous tax treatment of pension payments vis-à-vis lump sum payments. Structured Settlements provide a high degree of protection for the individual, for their family and for the community as a whole compared to lump sum payments which may be dissipated and render the injured individual reliant on the public income support and care services which may be very inadequate for those with high levels of support needs.

In an address delivered to the Structured Settlements Group in October 2002, the Minister for Revenue and Assistant Treasurer, the Hon Helen Coonan, canvassed the potential of Structured Settlements as a means of containing escalating claims on medical indemnity and public liability insurance, and achieving considerable social benefits by way of affordable premiums and better matching compensation with claimants needs. The attention now being given to these issues at Commonwealth level can be taken as a signal of possible new directions in funding care associated with insurances claims. It may be advisable to see where these new directions lead before advocating for funding reform in the general system.

Some cautions

Two caution signs need to be posted on the way to CDC to warn that the outcomes may not be exactly what is expected.

Savings on administration and overheads

One claimed advantage of CDC noted by Benjamin (2001) is that consumer direction achieves lower costs because it reduces or eliminates the need for home care agencies and case managers. The first and most general responses to this claim is that these costs are not “saved” but simply be shifted to the client and carer, or paid for by workers on lower wages with few benefits. US research reports that independent workers employed under CDC programs did less well financially than agency workers, but appeared to fare better in their work environment; these comparisons are however not clear cut as the great majority of

independent workers were family members. The possible consequences for quality of care have also been flagged in the US, but findings of one large scale study show improvements in a number of quality measures, including quality of life, or at least as good outcomes as agency services. The question about whether these benefits for recipients have been at the cost of dis-benefits to workers may take on more significance in Australia as unions take an increasing interest in the terms of employment and work conditions of the home care labor force, and especially in the area of occupational health and safety.

Some of the features of consumer direction that are seen as advantages by younger people with disabilities who want to manage their own care are disadvantages for older people. Recognition that people with disabilities are competent to manage their own care is central to enhancing autonomy and independence of younger people, but poses considerable difficulties for older people with mental impairments such as those associated with Alzheimer's Disease. This limitation was among several identified in US research into CDC specifically in aged care programs which found that take up among older people has been far lower than among younger age groups (Tilly & Wiener, 2001). That s qualitative study found that key stakeholders had more fears about the viability of CDC for older persons, and other studies have shown lower take-up among older persons. Passing the formal responsibilities for managing care to family members of older people may simply add to the strains they already experience, but there are examples of successful CDC programs for people with Alzheimers disease and their carers ((Mayer, Berson & Marks, 2000). Also, many of the CDC programs for individuals with developmental disabilities that are in place in US states, the UK, and the Netherlands tend to rely on the individual's support network to help the client manage services. The limitations of CDC for older cognitively impaired people who do not have a close family carer are evident; such individuals account for a very large segment of those with dementia, and the want of a family carer increases their likelihood of admission to residential care. Recognising these considerations may change the priority accorded to CDC by Alzheimer's Associations as they lobby to improve dementia care.

Discounting

A major consideration in paying cash benefits in lieu of services is whether a discount should apply, and what the level of discounting should be. One grounds for discounting is that some of the costs of delivering services no longer apply if the client opts to take the cash benefit. In the German scheme, cash benefits are discounted to 50% of the cost of services. Interestingly, the DNCB was originally set at a 50% discount against the cost of nursing home care. A similar discount could apply to any new cash alternative on the basis of overheads associated with payment of superannuation contributions, holiday, sickness and long service leave, and insurance premiums for occupational health and safety, and other administrative costs. CDC programs are especially likely to have adverse effects on workers if discounting is passed on as a loss of benefits in comparison to workers in agencies. A second grounds for discounting is that services that are cashed out should be costed at marginal rather than average cost, even though provision of services under CDC may not gain the economies of scale of agency services.

From the point of view of government, a decision on discounting will be influenced by the aims being sought in offering cash benefits. Discounting could be a savings measure, with government retaining the amount discounted, or could enable more clients to receive a benefit if the level of expenditure remained unchanged but was spread further by paying benefits at a lower rate than the cost of services.

A decision not to discount and to pay the full cost of services could be seen as a means of increasing the volume of care that existing clients received, provided that (a) recipients were able to convert the cash into services at a cost below that of the services foregone and (b) the cash could not be used to pay relatives for support that they were already providing. However, (a) could be seen as an overpayment and inequitable for those who for one reason or another continued to receive services, at a lower level, than those who took the cash, while (b) leads to intrusive scrutiny of relationships between the client-employer and their carer-employee to ensure that relatives provide more care than they did previously, or requires employment of non-relative care workers.

Which direction now?

The provision of aged care services, including dementia care services, has expanded and diversified enormously over time since the DNCB was established, and payment to caregivers has reappeared on the policy agenda in recent years. Some of the pros and cons of cash payments were discussed at the National Carers Association Conference in 1995, in the development of the National Agenda for Carers in 1996, and at the 2nd International Conference on Carers in 2000. Rather than focusing only on cash payments as central to consumer direction, attention now needs to be given to ways of realizing the advantages of consumer direction and minimizing the disadvantages. To this end, cash payments need to be made available not only as an all-or-nothing alternative to services, but as an option in the array of services, and alongside the promotion of non-cash related approaches to consumer direction in service delivery. Just as the adoption of case management in Australia combined elements of overseas programs and home-grown varieties, advancing CDC could well benefit from detailed assessment of the features of different international models that combine cash payments and other means of promoting CDC.

CDC is not a panacea that will solve all the problems across the aged care system; it certainly does not mean an automatic increase in funding or levels of support that may become available, and indeed carries some risks. It is best seen as one option among many when looking to innovations in community care in Australia, and as with most innovations, its effectiveness will depend on the design of CDC programs in relation to the purposes to which they are to be applied and the preparedness of governments, providers and consumers to take on experiments that are powerful enough to achieve more than marginal outcomes.

Having the choice to decide on the level of control that they want to exercise over their care is probably the main reasons for exploring ways of increasing consumer direction in Australia's community care programs for older people and younger people with disabilities. There are many ways of enhancing consumer direction in community care by giving individuals and their family members a greater say in planning and delivery of formal

services, short of cashing out the cost of services. And while cash benefits without any restrictions on how they can be spent may seem to provide the greatest scope for consumer direction, they may also bring a range of responsibilities for managing finances and workers that not all clients or families may be willing or able to take on.

The wider risk of increased consumer direction comes from a possible shift in responsibility for outcomes of community care programs from government and providers to clients and carers, and an undermining of the service infrastructure that may not be replaced with a care market in which consumers with small amounts of cash can find high quality bargains. Rather than lobbying for CDC within currently available levels of funding, increased consumer direction should go hand in hand with continued lobbying for increased funding, whether channeled into services or cash benefits.

The history of the Domiciliary Nursing Care Benefit and its successor, the Carer Allowance, provide many salutary lessons for those eager to promote increased consumer direction and especially cash payments. If those lessons are learned and applied in a very different contemporary policy and program context, and international experience is brought to bear on local circumstances, CDC is a direction that we should explore further. Our experience with innovation in community care, and especially in dementia care, suggests that there are good prospects for developing new options. Rather than just importing overseas models, we need to graft them on to the elements of consumer direction that already exist in current programs and so grow our own hybrids that are best suited to local conditions and that will strengthen our culture of care.

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Author's note

The Special Issue of *Generations*, edited by Robyn Stone and published in Fall 2000, includes 18 separate papers on Consumer Direction in Long Term Care. These papers provide a wide account of many aspects of CDC, but only the papers that are specifically cited in the present paper are listed separately here.

Detailed reports on CDC developments under the US Cash and Counselling Demonstration and Research Project can be accessed through the National Program Office at the Centre on Aging at the University of Maryland, www.inform.umd.edu/AGING

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Table 2: Elements of Consumer Directed Care in current Australian Aged and Disability Programs

| Present scope for consumer direction | Community Care Clients | | | Compensible Clients | |
|---|---|--|--|---|---|
| | Narrow | Medium | Extended | Constrained | Open |
| Current example | Clients whose carers receive Carer Allowance and who also use one or more HACC services, such as home help once a week and attending day care twice a week. | Package programs, incl. Community Aged Care Packages, Community Options and various Disability Packages | Clients with high care needs and receiving complex packages of services, combining a Package, Attendant Care and use of residential respite. | Client undergoing rehabilitation following accident, aimed at restoration of function and return to work. | Compensation awarded for injury from motor accidents and medical negligence/ misadventure, taken as lump sums. |
| Client group | CA recipients whose relative also receives HACC services, mostly a small amount of a single service. | Older clients assessed by Aged Care Assessment Team, as having care needs equivalent to low level residential care | Small group of clients with high care needs, estimated at around 2% of total HACC client population. | Clients injured at work or in motor vehicle accidents and undergoing rehabilitation. | Catastrophically injured clients awarded substantial compensation |
| Range of formal services | All HACC services | Multiple services, including personal care, several times a week. May include CA for carer | High levels of support, comprehensive care plan tailored to meet individual needs. May include CA for carer | Rehabilitation services prescribed by insurer, focused on return to work. | Not prescribed |
| Consumer input to decisions on service delivery | Spending of CA is unconstrained. Input to services mainly on scheduling, some input to tasks to be done. | Variable, highly dependent on approach of provider agency and client initiative | High but variable. May extend to selection of workers for attendant carers | Development of rehab plan | Injured individual or their guardian has total control over funds |
| Personal interaction with services | Assessment for CA; Very limited on-going contact required | One to one. Family carers may be involved | Intimate and extended in time. Family carers involved | Close interaction with therapists and insurer or agent | At discretion of injured individual |
| Flexibility | Limited; amount of CA too low to give much flexibility | Negotiated for changes in routines | On-going flexibility needed to enable adjustments in support | Individualised care, largely determined by therapists | Total, no requirements that funds be spent on care. |
| Cost of cash payments and formal services | CA currently \$43.85 p.w. Cost of services low, means tested fees | Medium – approx. \$200 per week, and means tested fees. | High, and means tested fees | High – specialist rehabilitation services. Not means tested or taxed | Dependent on individual choice as to whether/which services used. |
| Mode of payment, incl. cash benefits | CA paid directly to care; funding for services paid to provider agency. | Funding for services paid to provider agency; CA paid directly to carer | Funding for services paid to provider agency; CA paid directly to carer | Varies between States; Victorian TAC and Workcover reserve some funds for provision of care and manage funds for rehabilitation by reimbursing providers. | Paid to injured person as lump sum; responsibility for on-going financial management rests with individual or guardian. |

Table 3: Options for further development of Consumer Direction in Australian programs

| Option for development | Community Care Clients | | Compensible Clients | |
|------------------------------|--|--|--|--|
| | Cash-in-hand | Mixed models combining case management, cash and other elements of CDC | Constrained | Open |
| Relevant overseas models | UK cash option offered by all Local Authorities | Diversity of models ranging from: 1. Cash options in long term care social insurance schemes (e.g. Germany, Israel). 2. Small scale demonstration projects in different states of US, e.g. family governed care, cash and counseling demonstrations. 3. California In-Home Supportive Services Program, offering both agency and consumer directed care, with full delegation to consumer under agency financial management . | Difficult to identify overseas models as arrangements are highly specific to insurance arrangements in different jurisdictions | Structured Settlements in UK and Canada |
| Balance of cash and services | Cash out cost of services, client free to spend as chooses | Cash out cost of services, with further options for management of funds and service provision by 1. client directs services purchased with defined budget, but financial management remains with agency; 2. client receives cash for payment of specified services and becomes financial manager. 3. client receives cash benefit and spends as chooses, allows for paying relatives and purchase of any services. | Scope for increased consistency between states and between clients. Clarification of services to be covered by compensation vis-à-vis HACC and other programs. | Structured Settlement, with pension and payment for wide range of medical, rehabilitation and care services, as ordered by court in terms of Settlement. |
| Issues for consideration | 1. Individualised or flat rate payments 2. Discounting | 1. Specified or unspecified range of services 2. Allowing payment of relatives 3. Responsibility for employment of care workers 4. Role of case managers in assessing for and developing care plans may have significant cost impacts 5. Budget control for agencies | Consumer Directed Care options may apply to individuals who need long term support and who receive income support from insurance. | Complex medico-legal and actuarial issues. Long term management of funds on behalf of injured individuals. |
| Advantages | Clients offered choice of cash or services. | 1. Considerable potential for empowerment through consumer direction. 2. Increased flexibility in range and mix of support from formal and informal sources. 3. Possible gains in volume of support if achieve cost effective outcomes. | Integrating clients with different sources of funding into mainstream care program. Reduced oversight from insurer. | Increased protection for inured individuals and carers. Settlements applied to intended purposes Savings to community |

| | | | | |
|--|---|---|--|--|
| Disadvantages likely to affect take up | Small amounts of cash and difficulties of purchasing services may mean not worth the effort . | <ol style="list-style-type: none"> 1. May be difficult to find workers to work under conditions of consumer directed employment 2. Responsibility for financial management may be considerable. 3. Administrative complexity for clients, agencies and government if have multiple models with few clients each. | Insurers may be reluctant to reduce control over payment for services. | Injured individual foregoes lump sum. |
| Likely outcome | Lower take up among older clients compared to younger | Outcomes likely to be variable, depending on success of any pilot projects, definition of eligible clients, client preferences for different options, range of options offered and promotion by advocacy groups, providers and government. | | Take up dependent on limiting of lump sum payments |