



Increasing consumer choice in aged care services

A position paper

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February 2009



Brotherhood
of St Laurence

Working for an Australia free of poverty

Published by

Brotherhood of St Laurence
67 Brunswick Street
Fitzroy Vic. 3065
ABN 24 603 467 024

Tel: (03) 9483 1183
Internet: www.bsl.org.au

ISBN 978 1 876250 95 9

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Summary

The Brotherhood of St Laurence is committed to ensuring that all older Australians age well with dignity and security. Consumer-directed care offers new opportunities to achieve this goal. This paper reviews international and national literature on consumer-directed care and argues that evidence of improved outcomes for consumers and cost efficiencies warrants a trial of this approach in aged care in Australia.

The term *consumer-directed care* is used to describe a mechanism where consumers have direct control over their allocated funds and these can be used flexibly to meet their needs. Services and equipment can be purchased from traditional service agencies, and funds can be used for options outside the formal service system. Consumer-directed care provides greater control and choice to the consumer and reduces reliance on case management services. It is increasingly used in aged care internationally and in the Australian disability sector to promote independence and achieve cost efficiencies.

The need for change and additional options in aged care services is indicated by a number of factors. Demographic changes will increase the number of older Australians needing care in coming decades and this will require optimal use of available resources. Furthermore, there are strong demands from consumers and their advocates to have more choice and control than are currently available. Consumer-directed care provides another option when addressing these issues.

Evaluations of consumer-directed care projects report high consumer satisfaction and improved outcomes. Governments internationally are expanding this approach because it has resulted in greater independence and social participation for consumers, and because of its potential to deliver cost efficiencies. When consumers take a greater role in managing their allocated funds there are potential savings because of the reduced use of case management. Furthermore, when consumers have greater bargaining power they can achieve cost efficiencies by meeting their needs in more flexible and creative ways outside the formal service sector. 'Thinking outside the square' and developing innovative ways to meet needs often lead to improved individual outcomes. Improved outcomes were reported for the person concerned, their family and carers, and support workers.

The literature review identified key features of consumer-directed care projects that contributed to successful outcomes and cost efficiencies. These included: well-informed professional staff with positive attitudes; consumers' access to information and support services; manageable financial accountability requirements; available account-keeping services; protective mechanisms in place for the vulnerable; and support workers with appropriate training and working conditions.

Concerns have been raised in the literature about the possibility of older people, carers and support workers being at increased risk without ongoing supervision from case managers. There were also concerns about less accountability for public funds. To address these concerns, strategies have been developed which include an agreed plan for each person that details activities; regular reviews; support and financial accounting services being available; and having a nominated person responsible for a consumer with cognitive impairment.

This paper argues:

- It is time for consumer-directed care to be trialled in Australia to provide an additional option that would coexist with traditional agency-based services.
- Greater consumer choice could be achieved by the Commonwealth Government working with the aged care sector to develop, trial and evaluate consumer-directed care.
- The Department of Health and Ageing should undertake a pilot project offering 1000 consumer-directed packages in four diverse areas across Australia. Two approaches would be trialled simultaneously: one would use flexible individual budgets and the second would have

portability of funds. Both approaches could be implemented within the framework of the existing funding allocation mechanisms. It is proposed that the trials incorporate a wide range of programs including Community Aged Care Packages (CACPs), Extended Aged Care at Home (EACH), respite care, planned activity groups and residential care services. The aged care industry should be closely involved in planning the trials and regional advisory committees with consumer representation should be established to ensure the relevance and integration of the trials with regional service systems.

- A thorough evaluation needs to be undertaken by independent consultants.
- This initiative should be completed within two years and the findings used to inform future policy development.

The trialling of a consumer-directed care initiative would provide a valuable opportunity to explore the strengths and weaknesses of this approach for the Australian market. Consumer-directed care appears to offer a creative, innovative and effective option to meet the needs of older Australians in the twenty-first century.

Introduction

The Brotherhood of St Laurence is committed to ensuring that all older Australians can age well with dignity and security. It has a long history of service innovation and policy advocacy on ageing issues. This paper considers the desirability of, and possible mechanisms for, increasing consumer choice and control in the aged care system.

This paper examines the concept of consumer-directed care and other strategies for improving consumer choice. It examines national and international experiences from the aged and disability sectors and it considers the applicability of this approach for the Australian aged care system. The term *consumer-directed care* is used to cover a range of mechanisms that give people receiving public support greater control of the funds allocated to meet their care and lifestyle needs. One of the aims of consumer-directed care is to improve the responsiveness, flexibility and effectiveness of human services. It is hoped that this paper will promote debate about strategies to provide more consumer choice in the Australian aged care system.

Internationally, consumer-directed care has been adopted in a number of countries as a strategy to improve individual outcomes and cost efficiencies. Alzheimers Australia has argued for the introduction of consumer-directed care for several years (Tilly & Rees, 2007), and this possibility has attracted much interest within the aged care sector and within governments at the state and national levels.

The challenges posed by the growth of our ageing population and the future costs of care require thinking outside the historical square of policy responses. Consumer-directed care is a policy option worthy of serious consideration in Australia because of the positive outcomes achieved elsewhere. There are a number of implementation challenges, but international and Australian evidence suggests that consumer-directed care could be a worthwhile addition to the current suite of policy responses for our ageing society.

This paper examines the opportunities and challenges of introducing consumer-directed care into the aged care system in Australia. It follows an established tradition of adopting and adapting international models of care for Australian conditions (Howe, 2003). A draft discussion paper was circulated in August 2008 to a selection of stakeholders: industry peak bodies, aged care and carer organisations, and academics. This position paper was informed by their comments, but the views expressed are those of the authors.

Context

Recent Australian reviews of aged care have highlighted the complexity of current program and funding structures and argued for greater flexibility in responses to consumer needs. Significant documents are the Commonwealth of Australia's *Way Forward* (Department of Health and Ageing, 2004a), the Nous Group's *Moving to Centre Stage: Community Care for the Aged over the Next 10 Years* (2006) and the Allen Consulting Group's *Future of Community Care* (2007).

One of the drivers for change and innovation is the demographic changes that are expected to increase the number of Australians needing aged care in coming decades (Productivity Commission, 2007). There are concerns that the current model of aged care will not be financially sustainable due to these demographic changes (Department of Health and Ageing, 2004b; Commonwealth of Australia, 2007). However, it is not only financial concern that is driving change. Australian and international reports show that consumers want more flexibility and control than are currently available (Department of Health, 2007b).

Across Europe and in the United States of America, consumer-directed care projects are expanding in both the aged and disability fields. The rationale for their expansion is that consumers who are capable of and interested in managing their own supports are more likely to find individual ways of meeting their needs and will remain living independently in their homes longer than when supports are provided through traditional agency-based services (Office for Disability Issues, 2008; Wisconsin Department of Health and Human Services, 2008a). This is considered to be a 'win' for consumers and governments when consumers have access to funds that would otherwise have been used for agency infrastructure and staff. Consumer and advocacy groups support consumer-directed care because it increases choice and responsiveness to individuals' needs and results in higher levels of satisfaction (in Control, 2008a).

In the Australian disability sector, consumer-directed care is increasingly being adopted. It has been offered in Western Australia since 1988 through the Local Area Coordination project (Disability Services Commission, 2003). In Victoria, there was a recent trial of *Direct Payments* for people with a wide range of disabilities (LDC Group, 2007). The New South Wales Government is currently trialling consumer-directed care for people with physical disabilities (Fisher & Campbell McLean, 2007). Alzheimers Australia has argued for trialling of consumer-directed care in aged care for several years, and small initiatives have commenced within some agencies (Tilly & Rees, 2007).

What is consumer-directed care?

Consumer-directed care is an individualised approach that provides an alternative to case-managed services provided through service agencies. The consumer is given control over spending their allocated funds. Throughout this paper the term *consumer* is used to include those formally responsible for the welfare of the person receiving support if they do not have legal capacity. Consumer-directed care projects have various names including *direct payments*, *individual budgets*, *flexible funding*, *self-directed care*, and *self-directed supports*. When the term *flexible funding* is used internationally, it has a different meaning from the programmatic understanding of flexible care in Australia. Internationally *flexible funding* is used to describe an approach where consumers have direct control over their allocated funds that can be used flexibly to meet their needs. For the purposes of this study, the authors have adopted the term *consumer-directed care* to include the concepts covered by these other terms.

Guidelines vary, but typically greater choice and control are given to the consumer to purchase services from outside traditional support services as well as from within. There is an emphasis on finding creative and innovative ways to meet needs. All available resources are considered when planning to meet individual needs and preferences, including private and public funds and informal supports. Funds are used to support independence by employing support workers, participating in a wide variety of social activities, and purchasing equipment and technologies. Paid support workers can be recruited from informal networks as well as from the formal service sector.

Consumer-directed care projects often began when people with disabilities demanded to use their allocated money in ways that were not possible through existing service agencies. Since the 1960s, such projects in the US and Canada have supported people with disabilities to live in the community (Hutchison, Lord & Salisbury, 2006). They expanded into Europe and into aged care during the 1990s (Ungerson & Yeandle, 2007).

Projects usually commenced with a pilot that was evaluated and later expanded to become a viable service option alongside traditional agency-based services (Barnes, 2004; Conroy et al., 2002; Hutchison et al., 2006; Lindbloom et al., 2004; Riddell et al., 2006). Projects often encountered implementation challenges when adapting to the needs of their consumer group as well as to specific national and service system requirements. Change has been incremental and has required

policy leadership from government and involvement from service providers and advocacy organisations to be effective.

Ungerson and Yeandle (2007) group consumer-directed care in Europe into three categories:

- individual's funds held by the consumer to employ support workers from all sources including informal networks (family, friends and neighbours)
- individual's funds held by the consumer to recruit and manage support workers from the open labour market, but not from family
- individual's funds held by service provider.

Australian consumer-directed care projects have been categorised similarly, but with two differences (Fisher & Campbell McLean, 2007). First, they do not actively encourage recruitment of family members, although some do allow it. Second, when the consumer holds the funds, some projects require that support workers be engaged from approved service providers and not recruited from the open labour market.

International experience of consumer-directed care

United Kingdom

The UK Government is actively promoting innovative consumer-directed care models in disability and aged care. The drivers for change include escalating costs, rising levels of unmet need and dissatisfaction with traditional service provision (Commission for Social Care Inspection, 2008; Forder, 2007; Wanless & Forder, 2006).

In the disability sector, the *Community Care (Direct Payments) Act 1996* introduced significant change by guaranteeing people with a disability the right to an individual allocation once they were assessed as needing assistance. As power has devolved from the central government to England, Northern Ireland, Scotland and Wales, many implementation differences have evolved.

England is the strongest promoter of consumer-directed care and has initiated many innovative projects. In 2007, the heads of 19 government departments and key agencies agreed to provide all adult social care services in a more integrated manner (Department of Health, 2007b). Key entities involved include the Chief Secretary to the Treasury, the Secretary of State for Work and Pensions and the Chair of the Local Government Association. Local government, primary care, community-based health provision, public health, social care, housing, employment, benefits advice and education/training are involved. The policy makers are working towards combining all public funds allocated to an individual into one budget and having a single administration structure that will oversee spending controlled by the consumer according to an agreed plan. The aim is to provide personalised supports and opportunities for all adults to live independently. A 'first stop shop' is proposed for each local authority area to provide information and support that will be in convenient community locations and accessed by phone, letter, e-mail, internet. No single model is prescribed, but Direct Payments and Individual Budgets are noted as important examples of the new approach. These are the two main models of consumer-directed care in the UK and they are described below.

Direct Payments

The local authority assesses need and approves an allocation provided as a Direct Payment. In most areas, funding can only be used to employ support workers. A few areas allow funds to be used for social participation activities such as joining a club, or to purchase goods and equipment (Riddell et al., 2006). The consumer carries all employer responsibilities, recruiting support workers, paying insurances and taxes and keeping records. Some local authorities finance support centres to assist

with these responsibilities, and these are often peer or user led. Funding for these support services comes from central revenue and from levying charges on the consumer.

The take-up rate of direct payments in England is more than double that of other countries in Britain (Priestley et al., 2007). In 2007, 54,000 people in England were using direct payments (Commission for Social Care Inspection, 2008). The uptake is increasing but it has been lower than expected. Factors thought to contribute to the low uptake rate are:

- politicians and senior managers not ‘championing’ direct payments
- resistance to direct payments among staff groups
- complexity of local purchasing mechanisms
- administrative work and responsibilities for the consumer
- availability of support workers
(Knapp, 2007; Riddell et al., 2006; Stainton & Boyce, 2004).

Some consumers commented on the workload being a disincentive:

Inland Revenue class me as an employer. I do a tax return, holiday pay etc. My council doesn't do this for me. Lifestyles charity set it up for me ... it's depressing when you have to do all the paperwork. (Commission for Social Care Inspection (England), 2006b:19)

Individual Budgets

Individual Budgets were introduced following the low uptake of Direct Payments, and are attracting more consumers because they allow more flexibility. Four government departments (Health, Work and Pensions, Disability Communities and Local Government) are working together to provide an integrated model of care. In 2007, 13 local authorities piloted Individual Budgets (Department of Health, 2007a). A self-assessment of need and a plan approved by the local authority determine an individual's allocation. Funds can be used for social activities such as joining clubs, outings and purchasing equipment. In most areas, guidelines allow support workers to be recruited from family, friends and neighbours. Advice and accounting assistance are available, but these are paid for out of the allocated funds. In England, the long-term intention is for Individual Budgets to bring together funding from various social care funds into one allocation as discussed above (Knapp, 2007; Nicholls, 2007).

Individual Budgets are being piloted with older people, people with an intellectual, physical or sensory disability, and mental health service users (Individual Budgets Evaluation Network, 2007). In 2007, 1000 people in England were using Individual Budgets and numbers are expanding rapidly (Commission for Social Care Inspection, 2008). An extensive independent evaluation was underway in 2008 (Individual Budgets Evaluation Network, 2007).

Some of the Individual Budgets pilot projects in England, Scotland and Wales are sponsored by the not-for-profit organisation, in Control (in Control, 2008a). A distinguishing feature of in Control is that it allows funds to be spent on ‘anything’ as long as it is not illegal or gambling. A first phase evaluation involving 198 participants reported positive outcomes in health and wellbeing, quality of life and social inclusion (in Control, 2008b). In Control is developing impressive web-based resources for Individual Budget users. Budgets and plans can be amended and personalised on line; and templates are provided for writing support plans, support worker employment contracts, and electronic timesheets. A Good Employer Starter Kit and consumer guides to services and projects are also available. These electronic resources could be of use if the Australian Government decides to trial consumer-directed care in aged services.

Sweden

All Nordic countries have legislation that allows consumer-directed care. In Sweden, it is widely available in disability services, but opportunities for older people are only just beginning (Edebalk & Svensson, 2005). Disability service consumers have had a legal entitlement to manage their care since 1994. The disability legislation (*Certain Functional Impairments*, known as LSS, 1994), gives those under 65 years with disabilities the right to manage their funding and live independently (Swedish Institute, 2000). An assessment of personal support needs results in the person being allocated funds, with few restrictions on their use.

Experience in Sweden offers valuable insights into the take-up of this approach. Sixty per cent of people with a disability chose to receive traditional case-managed services from their municipality and most assistance was provided by rostered support workers; 25 per cent engaged staff from agencies (for-profit and not-for-profit); 12 per cent joined a cooperative; and three per cent self-managed (JAG Sweden, 2006).

Cooperatives are widely used in Sweden in areas such as housing and child care, and numerous cooperatives exist in the disability sector to support people using consumer-directed care to live independently in the community. These cooperatives are directed by people with disabilities, or others legally responsible who support them. Cooperatives employ administrative staff and generally charge fees of around five to seven per cent to provide all necessary information and support for consumers to recruit and manage support workers. The cooperatives manage the payroll and accounts and provide basic training for support workers. A team of support workers is often recruited to support one person with high needs to live independently. A team leader can be paid to coordinate the roster and is responsible if a worker is not available. A family member, usually the mother, can be the paid team leader who oversees the support team, and can live elsewhere and have their own full-time career (Laragy, 2006).

Sweden partially privatised aged care services and some 50 per cent of the 290 municipalities now purchase residential and community care for older people through a tendering process (Edebalk, 2008). Most tenders were won by large for-profit agencies and there was a tendency for monopolies to develop. To counter this trend, around 30 municipalities developed 'consumer choice' alternatives and two models have emerged (Edebalk, 2008). In one model, the municipality specifies service requirements, calls for tenders and selects a number of providers, most of which are large companies. In the second model, the municipality develops standards and authorises all providers who meet these standards to offer services. This model encouraged many small providers to enter the market. Small providers were allowed to offer restricted services to specific consumer groups, whereas their large competitors were not allowed to impose any restrictions. These small enterprises were popular with consumers and staff because they delivered individually tailored support services, and they were financially successful. This initiative resulted in many municipal support workers leaving to establish their own small enterprises (Edebalk, 2008).

Services in the disability field can charge different rates, but services for older people compete solely on quality. National legislation determines pay rates (Edebalk, 2008; Edebalk & Svensson, 2005).

Austria

Austria introduced major policy reforms in both the aged and disability sectors in 1993, and consumer-directed care became available to everyone needing ongoing support (Österle & Hammer, 2007). In 2004, self-directed care was used by 300,400 people: this constituted 4 per cent of the population. Approximately 90 per cent of those who self-directed their care lived in the community, while the remainder were in residential care. Consumer-directed care was available to all adults regardless of their type of incapacity, and 45 per cent were aged over 80 years. The number of people using consumer-directed care has increased sharply in recent years.

The aim of consumer-directed care in Austria is to offer an incentive for informal care to come from within the family and other primary networks and to enable consumers to remain living at home (Österle & Hammer, 2007). Allowances are not means-tested and they are paid directly to the consumer 12 times a year. Allowances are not, however, sufficient to support independent living. They are a supplement to families who are legally responsible for the welfare of their member needing assistance. Family legal obligations are enforced through the taxation system, with taxes imposed on close family members who are working, if residential care is required. Funds provided can be used flexibly for items such as house adaptations, specific dietary requirements and employing support workers. In practice, the consumer-directed care supplements are often used to employ support workers. Daughters, daughters-in-law and migrant workers from Eastern Europe are often employed. Support workers can be employed directly or recruited from agencies, most of which are not-for-profit.

United States of America

Consumer-directed care projects for older people have increased in the US in response to the growing needs of an ageing population. They commenced in the disability field in the 1970s (Hutchison et al., 2006) and were introduced into the aged sector in the 1980s (Kunkel & Nelson, 2006). After a slow start, self-directed aged care is now widely available across the US and is increasing. Many aged care services offer both consumer-directed care and traditional case management services (Kunkel & Nelson, 2006).

In the US, government financial assistance for people with few assets is provided through Medicare for hospital services and through Medicaid for community care and residential services. Private insurance schemes are widely used by those who qualify and can afford them. If people do not have private insurance, they use their savings to pay for care and apply to Medicaid when their assets are reduced. Medicaid and private health insurers generally have flexible guidelines and allow consumers to purchase services and supports of their choosing to assist them to live at home. Until recently, there was a complicated waiver system, requiring state-based consumer-directed care projects to apply to the federal government for permission to use funds flexibly. The federal government has simplified procedures in an attempt to expand consumer-directed care projects. There is considerable variation in such projects across the US: some states allow funds to be used flexibly to purchase a wide range of supports and services, while others are more restrictive and prescribe where services can be purchased (Feinberg, Wolkwitz & Goldstein, 2006).

Consumer-directed care was introduced into the US through a series of trials and evaluations. Positive findings from these demonstration projects encouraged their expansion. Four demonstration projects are reviewed below.

Choices for Independence

A large national demonstration project called 'Choices for Independence', funded by the federal government is currently underway (Administration on Ageing 2006). This US\$28 million project aims to keep older people living independently in their own home for as long as possible. Currently over 8 million older people are assisted under the *Older Americans Act 2006* and efforts are being made to modernise and improved the ways supports are provided. The project's objectives are to empower individuals to make informed decisions, provide more choices for those at high risk of nursing home placement and encourage behavioural changes to reduce their risk of disease, disability and injury. A public education campaign is being conducted and individual support is provided through 'one stop' resource centres. Consumers are advised on the best ways to use their private and public money to enable them to remain living independently. This initiative builds on the positive findings from other projects, including the Cash and Counseling Demonstration Program which is described below.

Cash and Counseling Demonstration Program

In the 1990s, the Robert Wood Johnson Foundation funded the ‘Cash and Counseling Demonstration Program’ and its evaluation. Consumer-directed care was made available to people in the aged and disability sectors in three states: Arkansas, Florida, and New Jersey. Seven thousand people were randomly allocated to intervention or control groups. Few restrictions were placed on how funding could be spent. It was used to employ support workers, purchase assistive devices or make home modifications. Most support workers were family members and spouses could be employed in some states, but not all. Almost everyone used the information and support services available (referred to as ‘counselling’). At some sites all support was provided free of charge, while others had minimal charges. Support was provided to develop plans, recruit and manage support workers and manage the accounts and the payroll. Evaluation reports showed high consumer satisfaction, especially when people were allowed to employ family members. Individuals using consumer-directed care received more services than those in control groups, and had improved health outcomes, with fewer respiratory infections, bed sores or pressure sores. Although some support workers recruited from within the family felt unappreciated for their work, overall the satisfaction of family and non-family workers was equally high (Dale, Brown & Shapiro, 2005; Foster et al., 2004; Otiniano, Herrera & Teasdale, 1996; Simon-Rusinowitz et al., 2005).

Michigan’s ‘Self-determination Initiative’

In 1997, Michigan was one of 19 states included in the ‘Self-determination Initiative’, a demonstration project for people with an intellectual disability, funded by the Robert Wood Johnson Foundation (Head & Conroy, 2005). A feature of this project was educating staff about the principles of self-determination and consumer choice. Consumers were supported to develop and implement plans using ‘person-centred planning’. Plans were then costed to produce an individual allocation. This differed from other places where an initial assessment determined the funding allocation. Participants could directly employ support workers or recruit from agencies. When workers were directly employed, funds were held and managed by a fiscal intermediary. Quality of life assessments were conducted before and after the introduction of consumer-directed care, and positive changes were reported. The study concluded that consumer-directed care enabled people to continue to live in the community, gave greater control over everyday activities like bedtimes, enhanced self-esteem, enabled more social activities with friends, and reduced costs by eight per cent. However, there were methodological difficulties that bring into question the cost reductions (Head & Conroy, 2005). These are discussed below in the section ‘Cost effectiveness’.

Wisconsin’s ‘Long-term Care’

The state of Wisconsin has trialled and promoted consumer-directed care in long-term aged care for some years. In 2006, it commenced a five-year project to integrate long-term care and health care services, aiming to maximise choice and to support older people to live at home for as long as possible (Wisconsin Department of Health and Human Services, 2008a, 2008b). All government funding allocations are combined with the person’s private funds, and all voluntary, informal and formal supports will be utilised. A ‘one-stop shop’ provides information and an individual plan specifies how funds can be spent. There are agreed limits to the use of funds, but regulations and accountability are kept to a minimum and funds can be used for ‘everything from sidewalk snow shoveling to nursing home care, and everything in between’ (Wisconsin Department of Health and Human Services, 2008b).

Advantages of consumer-directed care

The advantages of consumer-directed care reported in the literature are summarised below.

Improved responsiveness to individual requirements

The UK's Social Care Institute for Excellence conducted a meta-analysis of consumer-directed care evaluations. It concluded that consumers were generally more satisfied with this approach than with traditional support services because their individual needs and preferences were better met (2007). Having control of the allocated funds gave consumers more bargaining power with service providers, case managers and other professionals who became more responsive to their needs (Nicholls, 2007). Consumers liked this increased control because professionals 'become more like advisers, counsellors and brokers, guiding people to make better choices for themselves' (Leadbeater, Bartlett, & Gallagher, 2008:11). Consumers said, 'We want to remain in control over our own life and money ... even in a residential home' (Commission for Social Care Inspection (England), 2006a).

Simple changes, such as a support worker being available to assist consumers into bed at a preferred time or to undertake tasks as agreed, greatly enhanced consumers' quality of life (Gauthier, 2006; Laragy, 2005; Nicholls, 2007; Österle & Hammer, 2007). Examples given included:

- One person commented: 'I am now able to take a shower every day, something that was impossible before' (Gauthier, 2006:7).
- One man employed someone to fetch a meal from his local pub after rejecting 'meals on wheels' (Nicholls, 2007).
- A support worker cooked meals of the consumer's choosing: 'I am spoilt rotten again on the food front' (Carmichael & Brown, 2002:801).
- Funding was used to buy assistive technology, such as sensors that automatically switched on a light when the person got out of bed and a lifeline alarm to summon help if there was a fall (Nicholls, 2007).
- One group of consumers of mixed ages lived independently in their own flats and pooled their funding to buy services they needed. As the researcher noted: 'The resources involved made up a sizeable contract (of a scale which the local authority would normally have put out to tender), so there was real purchasing power involved' (Nicholls, 2007:10).

Consumer-directed care provided opportunities to people of all ages, including those who were older. This was captured in the quote: 'Age, in itself, is not a disability but it brings disabilities and we have to adjust ... We still want to be masters of our own destiny.' (Commission for Social Care Inspection (England), 2006a:1)

There were numerous accounts of consumer-directed care creating opportunities for increased social inclusion and social participation. Examples included:

- attending social activities, sporting functions and church services with a support worker, often at times when agency support workers were not available
- participation at a gym
- saving funds and going on a holiday
- shopping for clothes with the assistance of a support worker
- going to the pub with the assistance of a support worker

- visiting family with the assistance of a support worker (Carmichael & Brown, 2002; Laragy, 2005, 2006; Leadbeater et al., 2008; O'Donovan & Doyle, 2006; Poll et al., 2006).

Consumer-directed care was often used to complement other available resources, as shown in the comment: 'Direct Payments have been very flexible for me. I joined a gym, which is great. I pay for it but Direct Payments pay for my transport there and back'. (Commission for Social Care Inspection (England), 2006b:7).

A major advantage of consumer-directed care was that consumers could select their support workers (Carmichael & Brown, 2002; Gauthier, 2006; Revill, 2007). This was much preferred to being assisted by agency staff who changed frequently.

Direct Payments give me control. I now have a say in what I eat and drink, what I do and when I do it. I can choose carers that can help me to live my life. I can have continuity instead of a different carer every day. (Commission for Social Care Inspection (England), 2006b:4)

Cost efficiencies

A strong argument in favour of consumer-directed care is that it results in lower costs than do traditional agency-based services. Published research material is limited, but what is available suggests that governments are expanding projects because of cost savings (Leadbeater et al., 2008; Office for Disability Issues, 2007; Wisconsin Department of Health and Human Services, 2008b.) Without waiting for independent data, governments are expanding consumer-directed care projects in disability services based on their own analysis of costs and efficiencies.

A large US study randomly allocated service users to either consumer-directed care or a control group receiving services from a traditional agency (Head & Conroy, 2005). Accurate comparisons were difficult because many people assigned to the agency were left on waiting lists or received few services, and individual allocations could be increased or decreased when people moved to consumer-directed care. After allowing for these contingencies, savings of eight per cent were estimated, although the authors acknowledged that the accuracy of their findings could not be assured. Savings were also reported in the UK where in Control noted savings of 10 per cent (Leadbeater et al., 2008). The English Social Care Institute for Excellence (2007) conducted a meta-analysis of research findings and concluded that current evidence on efficiencies and costs of consumer-directed care is inconclusive and more work needs to be undertaken.

From a government perspective, consumer-directed care may provide a means of supporting more people at lower per capita cost while maintaining quality. In the US, consumer-directed care resulted in people being able to live at home longer and they usually chose less formal and less expensive supports to meet their needs (Wisconsin Department of Health and Human Services, 2008b). One US government program invested \$1.4 billion annually to support people to live at home and this leveraged an additional \$4 billion from other public, community and private sources for over eight million elderly individuals (Administration on Ageing, 2006). A senior County Council administrator in England said a key reason for expanding consumer-directed care was that it enabled people to remain living at home and it provided an alternative to more expensive residential care (Laragy, 2005).

Currently in Australia, a significant proportion of the funds allocated for support are used by service agencies for case management and administrative overheads. One Australian study found that these costs account for 45 to 50 per cent of the allocated funding (Summers, 2007): these are areas where potential savings could be investigated. There are other services in Australia and services overseas charging fees of less than 10 per cent of the allocated funds to provide information, brokerage and account keeping services for those who self-manage (Laragy, 2005 &

2008). After paying these fees, consumers have more funds to purchase personal care and other items compared with receiving support through traditional service agencies.

From a user perspective, consumer-directed care offers access to more funds and greater bargaining power. Consumers can seek opportunities to meet their needs in flexible and creative ways, with potential cost savings, because they are not restricted to purchasing services from the formal aged care sector. Effective use of consumer purchasing power is an important element of improved financial outcomes in this approach.

Demonstration and quantification of such potential savings should be an important element of any trial of this approach in Australia. Systematic research will be required to determine whether savings result, and if so, what factors contribute to this outcome.

However, support services for self-management only exist in limited locations. If self-managed care is to be made widely available, one option to be debated is that of government providing basic information, support and advisory services free of charge. This could be funded by a slight reduction in the value of individual care packages.

Transparency

An advantage of consumer-directed care is that it offers more transparency to consumers regarding the use of allocated funding. Increasingly, informed consumers are questioning the use of government funds that are allocated to them through service providers. For example, some consumers are questioning why they get so much less than the value of their total package in the cost of the services provided. Service providers have historically pooled available funds and shared them across all clients based on the provider's perception of need. In contrast to this, consumer-directed care will stipulate each person's individual budget and agencies will be directly accountable for this amount. The amount will be portable and consumers will be able to compare value for money across agencies. This approach will require more transparency from service providers and is likely to strengthen consumers' purchasing power.

Implementation issues

The literature review identified a range of issues facing governments and agencies when implementing consumer-directed care. This section considers these issues.

Promotion, information, planning and support

Information, advisory and planning services to assist and support consumers are common features of international projects. Information is generally provided regarding the:

- project guidelines and responsibilities
- amount of funds allocated
- location and availability of services for planning, case management, accounting, administration and recruiting support workers
- cost of services including hourly rates for support workers
- resources to assist recruitment and management of support workers
- resources to assist self-managing
- specialist community resources, equipment and supports
- responsible authority that can be contacted if problems arise.

Promotion and marketing are important to inform potential consumers and professionals about opportunities available. Information and support are most needed in the initial stages, but they

remain an ongoing requirement critical to achieving successful outcomes. Assistance needs to be appropriate, meaningful, accessible and timely; but this is not always achieved: 'There is a strong demand for information to be conveyed or explained by another person; a frequent criticism was "I was just given a list"' (Commission for Social Care Inspection (England), 2006b:8). Furthermore, guidelines need to be clear so that consumers know their rights and responsibilities (Dixon, 2007; Edebalk, 2007; Gauthier, 2006; Henwood & Hudson, 2007; Laragy, 2008; Nicholls, 2007; Reynolds, 2007; Riddell et al., 2006; Stainton & Boyce, 2004).

Planning support is provided free of charge (with limits) to consumers in some projects, while others charge fees for all services. There are concerns that charging for all information and support will result in a two-tier system: the most capable consumers will have access to information and will utilise a wide range of opportunities, while those less capable will be forced to use their funds to access help and consequently will have fewer resources to meet their needs (Individual Budgets Evaluation Network, 2007; Knapp, 2007).

Assessment and resource allocation

There are three approaches identified in the literature to the assessment of need and resource allocation in consumer-directed care projects. One approach is to assess needs first and later allocate funds according to the level of need. In most countries, an initial assessment by a professional determines the amount of funds allocated. A second approach is to develop with the consumer a plan which is later costed. Self-assessment is a third approach currently being trialled in the UK (in Control, 2008b). A detailed evaluation report on self-assessments is expected during 2008 and some initial user feedback has been released (Browning, 2007). Some consumers found that self-assessment was empowering and simple to use, while others wanted more information before they could make informed decisions. The application of self-assessment for older consumers with changing and increasingly complex care requirements is a matter that needs further investigation (Nicholls, 2007).

Developing valid and equitable assessment tools has been a widespread challenge. The difficulties of achieving these goals were highlighted in England where a standardised disability assessment tool was available that assigned each person to a level of need, but the funds allocated to each level varied. Local authorities committed resources according to the funds they had available and people with the same level of assessed need received different amounts in different areas (Laragy, 2005). Increasingly assessments are focusing on social goals in addition to personal care and basic medical needs (Gauthier, 2006), and these changes reflect the importance given by governments to promoting social inclusion and independent living.

Planning processes vary: some are simple and straightforward while others require a formal process that includes family, friends and professionals. Some projects require a written plan that specifies where funds can be spent and others allow funds to be spent at the consumer's discretion. In the UK, there has been considerable debate about the appropriate use of funds allocated. One instance received considerable media attention when Gavin Croft, a sufferer of multiple sclerosis with impaired vision, used part of his funding allocation to purchase a season ticket for a companion to accompany him to football matches and to comment on the game (Keegan & Ottewell, 2007; Benjamin, 2008). This arrangement was highly satisfactory for Croft and his wife. Croft enjoyed the football match and going to the pub afterwards with his Saturday afternoon companion; and his wife said, 'It gives me the only time I get off all week and I don't have to watch football in the wet and the cold'. The responsible Social Care Minister supported Croft's use of public funds. This example has strengthened the flexibility allowed to consumers in the UK and their right to decide how their allocated funds should be spent.

Financial and account management

The need for account-keeping support is largely determined by the accountability required by government. There has been a trend for governments to require detailed account keeping in the

beginning and to reduce their requirements over time. In the relatively new UK project 'in Control', consumers can spend allocated funds on anything as long as it is not illegal or gambling and accountability requirements are minimal. In most projects consumers are responsible for keeping accounts and providing reports. A minority of individuals have the expertise and interest to pay the accounts and report on expenditure, but most require services from an external person or organisation and do not want the responsibilities involved: 'Independent Living Services deal with payroll so I don't need to report back every week on how I spent the money. They also have all the knowledge about laws, sick pay and so on' (Commission for Social Care Inspection (England), 2006:7). Third parties such as cooperatives or financial intermediaries can manage all financial requirements as required.

A new profession of brokers has emerged in some parts of Europe and the US: they charge the consumer a fee-for-service to assist with planning and to purchase services on the consumer's behalf. There are some concerns that they are unregulated and their role and responsibilities are unclear (Henwood & Hudson, 2007; Knapp, 2007; Leadbeater et al., 2008). Independent planners and facilitators already exist in Australia for some individualised funding disability programs (LDC Group, 2007), and minimum qualifications and standards have been developed in some parts of Victoria. If such professionals become more influential in Australia, it would be important to consider what professional standards need to exist in the aged care sector.

Support workers

The literature review found advantages and disadvantages for support workers employed in consumer-directed care projects, and both are listed below. Some items are listed in both categories because circumstances varied between locations and between workers. For example, paid work to support a family member was warmly welcomed by some, but it presented difficulties for others. Many of the disadvantages existed in countries where labour laws do not protect minimum wages and working conditions to the extent that occurs in Australia.

Advantages of consumer-directed care for support workers included:

- Workers were recruited from informal networks and had opportunities not available to them in the wider labour market.
- Migrant workers gained employment that was unavailable elsewhere.
- Workers had higher levels of satisfaction when engaged to work for one person where they could negotiate duties and mutually agreeable times, compared with working for many clients through an agency.
- Workers stayed longer in their job working for one consumer compared with working for many people through an agency.
- Workers appreciated payment when caring for a family member as an alternative to having to seek paid employment elsewhere (e.g. mother cared for dying child).
- Workers could negotiate higher rates of pay for unsociable hours.
- Ethnic workers could arrange to work for consumers from their own community. (Carmichael & Brown, 2002; Dale, Brown & Phillips, 2004; Gauthier, 2006; Knapp, 2007; Laragy, 2006; Nicholls, 2007; Otiniano et al., 1996; Riddell et al., 2006; Simon-Rusinowitz et al., 2005; Stainton & Boyce, 2004; Ungerson, 2006).

Workforce concerns in some consumer-directed care projects included:

- Pay and conditions were below labour market standards.
- Cheap labour undermined working conditions of other support workers.
- Female migrant workers had difficulties negotiating working conditions and hours.
- Workers felt unappreciated working for a family member.

- Working for a family member reduced opportunities for employment in the full-time external workforce that would pay higher wages.
- Training and support were not always provided. (Dale et al., 2004; Laragy, 2008; Österle & Hammer, 2007; Otiniano et al., 1996; Ungerson, 2006; Ungerson & Yeandle, 2007; Williams, 2001).

It is clear that consumers can gain advantages from employing staff through consumer-directed care. Studies show that support workers also gained advantages, as long as they were protected from exploitation. The best working conditions occurred when support workers received award wages, were protected through workers' compensation and had health and safety training (Ungerson, 2006). The worst conditions were reported in Southern Europe where undocumented migrant workers had no alternative employment opportunities (Ungerson & Yeandle, 2007). This experience suggests the need to ensure that advantages to consumers are not at the expense of workers' industrial conditions.

Engagement of case managers

The introduction of consumer-directed care is a significant cultural and operational change requiring new understandings and work practices from all staff. Case managers lose a degree of control when they become planners and facilitators because they are hired, and can be fired, by the consumer. The consumer has full control if they are the legal employer, and still retains considerable control if using a third-party organisation as the legal employer.

In addition to concerns for vulnerable clients, case managers sometimes have concerns for themselves. They are concerned that their jobs might be threatened if consumer-directed care expands and consumers self-manage and directly employ their own workers (Henwood & Hudson, 2007). This is a realistic concern for individual workers, even though it is expected that service providers in general will continue to be needed. Secondly, case managers are sometimes concerned that they will be held responsible should anything go wrong for the client (Kunkel & Nelson, 2006).

Risk management strategies in services often hold workers responsible for client safety. In England, lines of accountability and responsibility were not always clear and local authority case managers sometimes carried responsibilities for Direct Payments consumers even though they had no 'hands-on' involvement or decision-making authority (Laragy, 2005). This was stressful for the case managers and a disincentive for them to authorise Direct Payments. Consumers sometimes find risk-averse attitudes of professionals and their employing organisations overly restrictive, as shown when one person was told by staff in a residential home, 'We can't let you go out as we can't take the risk that you might get run over' (Commission for Social Care Inspection (England), 2006a:1).

Clear guidelines and support for case managers are important to protect staff whose attitudes determine to a large extent whether their clients will take up consumer-directed care. The slow uptake of Direct Payments in the UK was partly attributed to the negative attitudes of case managers (Individual Budgets Evaluation Network, 2007). Case managers were often initially fearful and sceptical that consumer-directed care would be appropriate for their vulnerable clients (Carmichael & Brown, 2002). Generally, increased experience with consumer-directed care resulted in their fears abating (Kunkel & Nelson, 2006).

Suitability for specific populations

CALD populations

Consumer-directed care offers the opportunity for culturally and linguistically diverse (CALD) populations to organise culturally appropriate support (Glynn & Beresford, 2008; Kendrick, 2001; Nicholls, 2007). Reports from Britain and the US indicate that consumer-directed care is more

responsive to cultural differences than the 'one size fits all' approach of many traditional service agencies. According to one consumer:

I asked for a black carer but was only offered a white carer. I want someone who will understand my cultural needs. I can't lift my arms up. I wanted someone who could do my hair properly for me, a white carer can't do that. (Commission for Social Care Inspection (England), 2006b:5)

A Victorian disability study found that CALD disability groups were interested in consumer-directed care (LIME Management Group, 2005). The Western Australian Local Area Coordination project made consumer-directed care available to Indigenous and CALD participants. Reports were generally positive and there were high levels of satisfaction, but it was found that these groups needed more culturally specific information and support (Disability Services Commission, 2003).

Indigenous populations

Flexible funding program guidelines currently used for services to Aboriginal communities by the Department of Health and Ageing have some features of consumer-directed care. Consumer-directed care may be particularly applicable to Indigenous populations in providing a further vehicle for program flexibility.

The Department of Health and Ageing (2008) already provides flexible care through its Transition Care Program for Indigenous Australians leaving hospital. Flexible packages of service are provided for low intensity therapy, nursing and personal care. These principles could provide the foundation for the broader application of flexible care.

Carers

The critical role of family and other informal carers in providing aged care is widely recognised. In England, it is estimated that unpaid care would cost £67 billion if purchased from formal services (Moullin, 2007). Carers often face financial and other hardships because their caring reduces their opportunity to participate in the paid labour market (Moullin, 2007; Simon-Rusinowitz et al., 2005; Williams, 2001).

Some carers like consumer-directed care when it allows them to be formally employed and be for work previously done without payment (Individual Budgets Evaluation Network, 2007). They also like being able to select support workers and directly negotiate duties and schedules, having access to more funds previously paid to agencies, and having flexibility to take up opportunities for social inclusion as they arise. In some instances, consumer-directed care added to their burden because of the increased demands and responsibilities for planning and financial record-keeping previously done by case managers (Dale et al., 2004). Also, carers who received below-award wages and conditions sometimes felt unappreciated and more stressed than non-family workers (Ungerson & Yeandle, 2007). The needs of carers should be considered when developing an Australian model of consumer-directed care.

Consumer-directed care in Australia

Consumer-directed care is already available in a number of disability projects across Australia and this experience can inform the debate about its introduction into aged care. The Western Australian Local Area Coordination program, commenced in 1988, is Australia's largest program. The last review was undertaken in 2003, when a comprehensive meta-analysis of 17 separate studies concluded that consumer-directed care resulted in a wide range of positive outcomes (Disability Services Commission, 2003).

Victorian Disability Services trialled and evaluated a small consumer-directed care project in 2006 (LDC Group, 2007). Allocated funds were paid into the consumer's bank account and could be

used flexibly for a diverse range of activities as long as high levels of financial accountability were met. All participants successfully managed their own funds and reported high levels of satisfaction. Factors that contributed to the project's success were the consumers' involvement in developing the project's design and policies, having a detailed plan for each participant that was subsequently costed, and having access to a project worker for information as required. The evaluation concluded that the project was successful and recommended that it be expanded. The report details policies and procedures that could be useful when considering the introduction of consumer-directed care into aged care.

The New South Wales Department of Ageing, Disability and Home Care is currently trialling consumer-directed care for people with physical disabilities to employ support workers (Fisher & Campbell McLean, 2007). Three models are being used: 'direct funding' to the consumer who carries all responsibilities; a 'cooperative model' where funds are managed by a service provider while the consumer recruits and becomes the legal employer of support workers; and the 'employer model' where funds are paid to a service provider that employs support workers and consults with the consumer as appropriate. An interim report indicates positive outcomes on a diverse range of measures including satisfaction, wellbeing and social and economic participation. The final evaluation report is expected later in 2008.

In the aged care sector, UnitingCare Community Options in Victoria is designing a consumer-directed care project to commence in 2009. Consumers will be able to choose from options ranging from traditional case management to having control of their funds and be able to plan and purchase their own services. Information and support services will be available. Existing state and Commonwealth aged care funding packages will be pooled for each consumer and available to be used flexibly. The evaluation will examine the efficacy and sustainability of this service model and its ability to improve consumer satisfaction, health outcomes, and quality of care across the continuum of health and social care settings.

An Australian approach

This review of consumer-directed projects has highlighted a range of positive outcomes, but it has also raised a number of implementation issues to be addressed if such an initiative is to be introduced in Australia. Our analysis points to six key issues which need to be considered in the design of an Australian approach. These are:

- projected uptake rate
- informing, supporting and empowering consumers
- engagement of case managers
- accountability and reporting mechanisms
- managing risks and vulnerabilities
- workforce issues.

Projected uptake rate

Australian aged care providers already offer a wide range of innovative and creative projects, and international experience indicates that the traditional services will play an important ongoing role. For example, 60 per cent of Swedish disability consumers chose to purchase traditional services from their municipality when they had many choices (JAG Sweden, 2006).

While consumer-directed care will not be suitable for everyone and many will prefer traditional agency provision of services, there are growing numbers of consumers who want the flexibility and opportunities it provides. Many also want access to funds that are currently spent on case management and agency overheads.

International experience suggests that some service providers will see consumer-directed care as an opportunity, while others will feel threatened by it. The attitudes of professionals towards consumer-directed care will impact on its uptake rate (Commission for Social Care Inspection (England), 2006a). Consumer-directed care requires a significant cultural shift in professional practice and it requires new roles and operational systems. To meet these challenges, training and support are essential to assist service providers and support workers to adapt (LDC Group, 2007; Social Care Institute for Excellence, 2007). A case can be made for some transitional funding to provide incentives for service providers to meet extra costs for training, marketing and operational changes related to individual accounts:

Providers – need to be encouraged to embrace the new agenda, develop their vision for developing person-centred services that support choice and build partnerships and alliances to facilitate change ... Though well placed to develop new models of care, there are particular challenges for providers who are competing in a market where there is a shortage of people with the right skills and a need for better information about what works. (Commission for Social Care Inspection (England), 2006a:13)

Consumer-directed care will be attractive to aged consumers who are seeking greater choice and control of available funds to support their care requirements. There is little evidence to indicate what factors will predict which consumers will take up this opportunity with respect to socioeconomic status, age and cognitive capacity. There is an untested assumption that higher uptake will occur among consumers aged 65 to 80 who have the capacity to manage their own affairs, or have families willing and able to negotiate service systems on their behalf. This assumes that older consumers will have less family support and they will be unable or disinterested in negotiating services and being accountable for their funding package. Further evidence is needed to test these assumptions.

Based on international experience detailed above, consumer-directed care is an option that is likely to be taken up by no more than 25 per cent of the eligible ageing population when there is effective implementation. However, this is a significant proportion of a growing service-user population. Effective marketing campaigns will need to be considered to encourage uptake.

Some service providers are already adopting choice and independence creation principles in their practice; and they will respond eagerly to the opportunities that consumer-directed care offers for their clients. For others, the competitive discipline offered by consumer-directed care will provide an incentive to adapt their services to enhance consumer choice and control.

Informing, supporting and empowering consumers

Providing support to develop individual plans based on each person's needs and wishes needs to be considered in any Australian project. Planning support is provided free of charge to consumers in some projects (with limits), while others charge fees for all services. There are concerns that charging for all information and support will result in a two-tier system (Individual Budgets Evaluation Network, 2007; Knapp, 2007): the more capable consumers will have access to information and will utilise a wide range of opportunities, while those less capable will be forced to use their funds to access help and consequently will have fewer resources to meet their needs. Providing information and support services free of charge overcomes this difficulty and this could possibly be done through new 'one-stop shops' similar to those proposed by *The Way Forward* report (Department of Health and Ageing, 2004a).

Locally based, peer support projects sponsored by governments were found to be effective in providing this assistance internationally (Social Care Institute of Excellence, 2007), and should be considered in Australia. Existing aged care service providers may be able to offer some or all these services. However, international experience shows that extensive staff training is required for existing services to make the cultural shift to consumer-directed care to ensure it is not just 'business as usual'. Where consumer-directed care has been introduced overseas and in Australian

disability services, new positions such as planners, facilitators, financial intermediaries and commercial trust companies have emerged. If consumer-directed care is introduced into aged care, it will be important to ensure high standards and to avoid monopolies, which could increase costs.

Engagement of case managers

Case managers will continue to play an important role if consumer-directed care is introduced. However, changes in roles and responsibilities will be required. It will be important to engage case managers with the positive aspects of consumer-directed care. Case managers will need information, education and support to learn about consumer-directed care and be responsive to the opportunities and challenges it presents (Henwood & Hudson, 2007; LDC Group, 2007).

Accountability and reporting mechanisms

A person-centred plan that is regularly reviewed is used in many projects as the basis for safeguarding vulnerable people and to account for public funds. Although evaluations of consumer-directed care show that instances of fraud or defaulting consumers have been comparatively few (Caldwell, 2007; Simon-Rusinowitz et al., 2005; Social Care Institute for Excellence, 2007), mechanisms are needed to ensure the welfare of vulnerable older people and to provide accountability for government funding. Reliable data reporting has been a strong feature of the aged care program and should be retained in any new initiative. One of the implementation issues in Australia is to identify simple, inexpensive mechanisms that enable consumers to meet legislative and regulatory requirements. Compliance rates and financial accountability should be among the issues considered in pilot evaluations.

A minimalist approach to financial accountability requirements is increasingly being adopted by governments after they become comfortable with the concept of consumer-directed care (Henwood & Hudson, 2007). Projects often commence by requiring extensive documentation and financial accountability and these requirements are reduced over time (Carmichael & Brown, 2002; Nicholls, 2007; Stainton & Boyce, 2004). This may be for practical as well as philosophical reasons. Maintaining detailed accounts is onerous for consumers and overseeing compliance is costly for governments. The Swedish disability sector does not require detailed accounts, nor does the British *in Control* project that allows funds to be spent on anything that is legal except for gambling (in Control, 2008a). The expansion of the large US Wisconsin project was guided by the motto 'Keep it simple' (2008b).

Computer software that enables people to record the necessary data for consumer-directed care is available elsewhere and could be adapted for Australian use or new material could be developed. Web-based technology offers opportunities for care plans, financial records, transfer of funds, and financial reports to be managed efficiently. If government requires an audited statement of accounts, they could direct consumers to freely available software to facilitate the process.

Managing risks and vulnerabilities

The possibility has been raised that vulnerable older people may be at increased risk of neglect, isolation or abuse and exploitation from family, unscrupulous service providers or support workers if they do not have oversight and the protection of a case manager (Dixon, 2007; Reynolds, 2007). Consumer-directed care evaluations to date have not revealed evidence to substantiate such concerns (Simon-Rusinowitz et al., 2005; Social Care Institute for Excellence, 2007). However, appropriate mechanisms will be needed to ensure these problems do not emerge.

Another consideration is the risk of increased social isolation for some consumers. Social isolation is already a problem and review mechanisms and safeguards would need to be in place to decrease and not exacerbate this problem. Generally, consumer-directed care has been found to increase social participation, but on occasions it has resulted in increased social isolation. In the disability field, one mother found that her son, using consumer-directed care in England, missed spending

time with peers: 'My son is out constantly but sometimes he would just like to be in a group activity rather than on his own with a carer. I like Direct Payments and it's working well for us but I do think it isolates him.' (Henwood & Hudson, 2007:21). Appropriate information about community activity opportunities will need to be provided.

A further concern is that allocations may not be adequate to meet personal needs. Consumers could be left isolated and vulnerable at home if there is no case manager to notice inadequate resourcing and no-one to advocate on their behalf (Brennan, 2006; Gauthier, 2006; Knapp, 2007). If funding is not adequate, basic needs may not be met and older people could be at risk: 'If people are in desperate need but social services can't come it's risky. People need to push but we don't have the confidence.' (Commission for Social Care Inspection (England), 2006a:7)

The Australian aged care sector can learn from local and overseas experiences when considering appropriate mechanisms to protect the vulnerable using consumer-directed care. In England, detailed planning and risk management tools are used to promote choice and independence while maximising safeguards (Department of Health, 2007a). All relevant stakeholders (the person, family members, friends and professionals) come together to develop a mutually agreed plan, and responsibilities and risks are shared. When people have reduced capacity to make decisions, a responsible person is nominated to have oversight and be accountable. Some projects establish 'circles of support' or legal 'trusts' (McConkey, 2005). It is acknowledged that some degree of risk can be acceptable if it is considered by all those involved to be in the best interests of the person concerned. When people are capable of managing their own lives, they do not need the same protections, and overzealous monitoring would be counter to the principles of self-determination and consumer control. Striking a reasonable balance between providing opportunities and managing risk will be an ongoing challenge, 'It's not possible for life to go on without taking reasonable risk. But there are grey areas that people should get support on how to balance the risks without sacrificing independence.' (Commission for Social Care Inspection (England), 2006a:3)

In Sweden, a 'trustee' is allocated to every person with a disability who has reduced decision-making capacity, and the trustee is legally responsible for the person's welfare. This system is generally considered to be effective in mitigating against isolation and neglect, but as a family member is usually the 'trustee', there is no protection against family abuse or exploitation.

In the Victorian Disability Services consumer-directed care project (LDC Group, 2007), the project coordinator provided oversight and a detailed risk management strategy was developed. This covered systemic issues such as policies, procedures and strategic planning; duty of care; and individual financial accountability that included monitoring of bank accounts and financial acquittals. The evaluation report provides details of these mechanisms and it could assist the development of consumer-directed care in the aged sector.

Workforce issues

One of the major challenges facing the aged care sector is the availability of suitably trained support workers. Consumer-directed care will face the same challenge and consumers will be competing with service providers for skilled staff. One advantage of consumer-directed care is that it can tap into informal networks, thus increasing the pool of potential workers.

Any model of consumer-directed care in Australia needs to maintain the informality and flexibility of employment arrangements without jeopardising the support workers' conditions. Australia has stronger industrial laws than exist in Europe and the US and it does not have their large pool of illegal migrants. However, some support workers in Australia, especially migrant women, found it difficult to negotiate terms and conditions (Laragy, 2008). Mechanisms to prevent exploitation need to ensure that staff are engaged according to an industrial award or employment agreement; and if a consumer does not want, or is not able, to assume the responsibilities of an employer, a 'third-party' organisation can be the legal employer.

Scope of reform in Australia

This paper has argued that consumer-directed care offers real prospects of improving the responsiveness of aged care services and increasing cost efficiencies and that there are strong grounds for trialling this approach in Australia. It proposes that a consumer-directed care initiative be developed and trialled in Australia by the federal government. There are several options for implementing consumer-directed care in Australia and the suggested elements of a framework for a consumer-directed care initiative in Australia are set out below.

A consumer-directed care initiative should involve:

- 1 consultation with key stakeholders
- 2 development of a pilot specification for the trial in four locations across Australia detailing the approaches to be implemented and its evaluation
- 3 allocation of funding for the trial
- 4 an agreed timeframe for considering the further application of this approach to the aged care system once the pilot and its evaluation have been completed.

It is proposed that two approaches to increasing consumer choice in community Australian aged care services be trialled. The first approach should be based on individual budgets and the second on portability of funds. Both approaches could be implemented within the framework of the existing funding allocation mechanisms using the Aged Care Funding Instrument (ACFI), and both could be trialled in four designated 'demonstration regions'. It is proposed that the trials incorporate a wide scope of programs including CACPs, EACH, respite care, planned activity groups and residential care services. A temporary exemption from some provisions under the *Aged Care Act 1997* with regard to program entitlements may be required. The intent, however, would be to fund all costs through agreed packages and minimise cross-program subsidisation.

In the *individual budget* approach, consumers would be allocated a budget and could purchase services from the formal aged care service sector or from alternative sources. Spending guidelines should be flexible and appropriate accountability requirements would need to be developed. Specialist information, support and advisory services funded by government (not the individual) would need to be developed as part of such a trial.

In the *portability of funds* approach, consumers could use their allocated funds with any provider eligible to receive funds under the *Aged Care Act 1997* and the *Home and Community Care Act 1985*. The consumer could choose to move their allocated funds from one service provider to another. This would be a voucher system rather than the current mechanism of packages allocated to service providers. Allocated funding could only be used to purchase services from approved providers. Assessment, information and advisory services would need to be available as required to assist clients.

To test this approach in Australia, it is recommended that the Department of Health and Ageing undertake a pilot project over the next two years offering 1000 consumer-directed packages, with 250 consumers in four different regions. The pilots should be undertaken across a range of geographical settings including metropolitan, regional and remote areas. A thorough evaluation of the pilot project needs to be undertaken by independent consultants. After the initial trial and evaluation of the consumer-directed care initiative, the prospects for wider implementation should be considered.

Future possibilities

The application of consumer-directed care to residential care is a further consideration to be considered in the future. It would open up greater possibilities for consumers to choose between community and residential care options. The ACFI instrument could continue to be used to assess

and allocate funds commensurate with a person's level of need and capacity and the person could choose to purchase residential, respite or community services, or a mixture of these. The development of an ACFI-like instrument for community-based care would assist in the determination of the level of funding based on level of need. Having more options would empower the consumer because they could decide the best way to meet their needs. Such an option would allow the Commonwealth to use the same allocation method in residential and community care and ensure equity across program guidelines.

Recommendations

This paper reviewed literature on consumer-directed care and concluded that this approach has the potential to improve consumer outcomes, service responsiveness and cost effectiveness in Australian aged care services. It proposes that a consumer-directed care initiative be developed by the Department of Health and Ageing as a strategy for trialling this new approach. The lessons learnt from this trial should inform aged care policy development.

This paper has argued that:

- It is time for consumer-directed care to be trialled in Australia to provide an additional option that would coexist with traditional agency-based services.
- Greater consumer choice could be achieved by the Commonwealth Government working with the aged care sector to develop, trial and evaluate consumer-directed care.
- The Department of Health and Ageing should undertake a pilot project offering 1000 consumer-directed packages in four diverse areas across Australia. Two approaches would be trialled simultaneously. One approach would use flexible individual budgets; and the second would have portability of funds to be used through aged care service providers. Both approaches could be implemented within the framework of the existing funding allocation mechanisms. It is proposed that the trials incorporate a wide range of programs including CACPs, EACH, respite care, planned activity groups and residential care services. The aged care industry should be closely involved in planning the trials, and regional advisory committees with consumer representation should be established to ensure the relevance and integration of the trials with regional service systems.
- A thorough evaluation needs to be undertaken by independent consultants.
- This initiative should be completed within two years and the findings used to inform future policy development.

The trialling of a consumer-directed care initiative would provide a valuable opportunity to explore the strengths and weaknesses of this approach for the Australian market. Consumer-directed care appears to offer a creative, innovative and effective option to meet the needs of older Australians in the twenty-first century.

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