



Adjusting to Consumer Directed Care

The experience of Brotherhood of St Laurence
community aged care service users

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2016



**Brotherhood
of St Laurence**

Working for an Australia free of poverty

The Brotherhood of St Laurence is a non-government, community-based organisation concerned with social justice. Based in Melbourne, but with programs and services throughout Australia, the Brotherhood is working for a better deal for disadvantaged people. It undertakes research, service development and delivery, and advocacy, with the objective of addressing unmet needs and translating learning into new policies, programs and practices for implementation by government and others. For more information visit <www.bsl.org.au>.

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Summary

Australia's approach to aged care provision to support people living in their own home has recently undergone radical change. At the core of the reform is the concept of self-directed care, which offers aged care clients individual choice and control of their government-subsidised Home Care Packages. The framework for the changes is Consumer Directed Care (CDC), which is defined as:

... a way of delivering services that allows consumers to have greater control over their own lives by allowing them to make choices about the types of care and services they access and the delivery of those services, including who will deliver the services and when (DSS 2014, p. 7).

The transition to CDC commenced on 1 August 2013. All new Home Care Packages were mandated for delivery under the CDC framework from 1 July 2014, and all existing packages from 1 July 2015.

A proprietary BSL model was developed for the delivery of services under the CDC framework. The model offers consumers a choice of three levels of autonomy, which define the amount of consumer self-management and which influence the total amount of money available to purchase services.

A formative evaluation of the BSL model and the BSL transition to CDC was conducted by the BSL Research and Policy Centre Inclusive Ageing team using an action research approach that tracked the challenges faced during the transition and their resolution.

This report focuses on the CDC experience of BSL Home Care Package consumers and their adjustment to the new model of service delivery under the Consumer Directed Care framework. Interviews with consumers and carers explored their understanding of CDC and the BSL model of delivery, the suitability and adequacy of information provided to them, the impact of the new arrangements on the services they received and activities they accessed, and their attitudes to the introduction of individual budgets and monthly financial statements. It became clear that at least four factors influenced how an individual experienced and adjusted to CDC:

Capacity to manage a CDC package

The CDC approach to home care package management is complex. Consumers who can self-manage their package require less case management assistance, which releases more funding for services and activities. Consumers who do not have the capacity to self-manage because of cognitive impairment, or who lack the literacy, numeracy and other life skills to take control of their package, had to allocate a larger portion of their subsidy to case management fees. In addition, their understanding of the CDC model and their capacity to interpret information given to them, for example monthly financial statements, was often compromised.

Adequacy of available funding to meet care needs

Consumers whose care needs could be met within the available Home Care Packages subsidy fared better than those who had more complex care needs. The shift to individualised budgets meant that service providers could no longer reallocate unspent funds to support these consumers. Some consumers were able to call on their own resources or assistance from family to supplement the package. Those without additional resources or other support had to prioritise and reorganise their services to fit within their individual subsidy.

Availability of support networks outside BSL

Many BSL aged care services consumers experience multiple disadvantages, including chronic health conditions and social isolation. Consumers who have a carer to assist in the management of their package and a wider support network of family and friends are less reliant on BSL support and as a result have access to more funds than those without similar support.

Consumer attitudes

Consumers exhibited a range of responses to the changes brought about by the implementation of CDC. While many were keen to take an active role, others were not and, regardless of their capacity, preferred to hand responsibility to their case manager. Some consumers were more willing than others to work with their case manager to find creative ways to make the necessary adjustments to their services to manage their budgets.

The next stages in the Australian Government's reforms to aged care services take effect in February 2017. Home Care Packages will be allocated directly to consumers, who will select the provider they want to assist them to manage their package. They will have the right to change provider if they think they will be better served by doing so.

CDC may yield benefits for capable adults, *provided* they have the means to exercise meaningful choice and control. With adequate support, it has the potential to empower service users and fits well with the capabilities approach advocated by BSL. However, to avoid increasing the burden of risk for consumers, carers and their families, CDC must be accompanied by practical support such as administrative, financial and professional services to enable positive risk taking and to safeguard against abuse, as well as continued investment in appropriate governance and regulation.

1 Introduction

Context

Australia's approach to aged care provision in the community has recently undergone radical change. At the core of the reform is the concept of self-directed care, which offers aged care clients individual choice and control of their government-subsidised Home Care Packages. The framework for the changes was Consumer Directed Care (CDC) and the first stage of its national implementation was scheduled for the period August 2013 to 30 June 2015 (DSS 2015a). The transition from the Community Aged Care Package Program commenced on 1 August 2013. All new Home Care Packages were mandated for delivery under the CDC framework from 1 July 2014, and all existing packages from 1 July 2015.

The Brotherhood of St Laurence was an early adopter of consumer directed care. Its preparations for the introduction of CDC commenced in late 2009 with a literature review of self-directed care (Laragy & Naughtin 2009), soon followed by participation as an industry partner in People at Centre Stage (PACS), an Australian Research Council Linkage Project (2008–2011) led by Deakin University designed to anticipate the CDC. BSL also participated in the Department of Health and Ageing pilot programs in 2010–2012. This experience led to the development of the BSL proprietary model for CDC, which was trialled between March 2014 and June 2015.

This evaluation

A formative evaluation of the BSL model and the BSL transition to CDC was conducted by the BSL Research and Policy Centre Inclusive Ageing team using an action research approach that tracked the challenges faced over the 15 months and their resolution. The purposes of the evaluation were to inform BSL Retirement and Ageing Services about the efficacy and sustainability of the BSL CDC model and to contribute to broader debates about individualisation of aged care. The evaluation considered:

- impact on consumers
- impact on staff
- financial viability/sustainability
- new technologies and systems.

This report focuses on the CDC experience of BSL Home Care Package service users, or 'consumers' to use the Department of Health policy terminology.

The move to consumer directed care

There has been a trend towards greater user control of human services in fields such as disability and aged care, particularly in countries embracing neoliberal philosophies of

competition, market-led service provision, the commodification of services and the transfer of the responsibilities and risks associated with free choice to individual consumers.

In Australia, steps towards reform of aged care have been underway since the early 2000s, with a government-initiated review of community care programs released as *The way forward* in 2004 (The Allen Consulting Group 2007). This was followed by a Productivity Commission Inquiry that culminated in the definitive report *Caring for older Australians* (Productivity Commission 2011). The report's recommendations led to a 10-year reform program, Living Longer, Living Better, which aims to create 'a flexible and seamless system that provides older Australians with more choice, more control and easier access to a full range of services, where they want it and when they need it' (DSS 2013, p. 5).

A major facet of reform is the shift to consumer directed care, which has been embedded in the User Rights Amendment (Consumer Directed Care) Principles 2014 of the *Aged Care Act 1997*. Consumer directed care is defined as:

... a way of delivering services that allows consumers to have greater control over their own lives by allowing them to make choices about the types of care and services they access and the delivery of those services, including who will deliver the services and when (DSS 2014, p. 7).

The claim that individualised, self-directed health care can improve service users' wellbeing and quality of life rests on a handful of evaluations of individual budget pilots rolled out in the United Kingdom. Among them are the internal evaluations undertaken by In Control (Poll et al. 2006; Hatton & Waters 2011) and the national evaluation of Putting People First by the Individual Budgets Evaluation Network (IBSEN) (Glendinning et al. 2008). While the scope of the UK evaluations has encompassed all groups accessing 'personalised' care and support, including people with disability, some findings pertain particularly to older adults.

In Australia the only published evaluations of self-directed aged care have been of the initial consumer directed care initiative (KPMG 2012), the CDC trial commissioned by the Department of Health and conducted by KPMG in 2014 (KPMG 2015) and the People at Centre Stage project which included the design, trial and evaluation of a model of self-management in anticipation of the formal introduction of CDC (Ottmann, Laragy & Allen 2012). While the PACS project predictions proved largely accurate, nevertheless it was handicapped by having to second-guess some of the government guidelines. The KPMG evaluation too has self-confessed limitations since the trial was conducted very early in the transition period, over a very short time span and at such short notice that providers had very limited lead time 'to develop their approach to CDC and to select participants' (KPMG 2015).

The CDC approach to aged community care

While the terminology used for user self-management of social care is diverse and varies across countries, it appears that the Consumer Directed Care program in Australia has drawn heavily on the UK policy framework which currently uses the term 'personalisation', a care approach described by the Department of Health (UK) in 2008 as 'every person who receives support, whether provided by statutory services or funded by themselves, will have choice and control over the shape of that support in all care settings' (Community Care website, Department of Health UK 2008).

In promoting an individualised market-driven system of home care, the Australian Government's rationale was:

Consumers have managed their own lives for a long time. They should be empowered to continue to manage their own life by having control over the care and support they receive (DSS 2014, p. 8).

The Home Care Packages Programme has been designed to reflect this principle.

The Home Care Packages Programme

The Home Care Packages Programme was introduced nationally in August 2013. It replaced the Community Aged Care Package Program (Department of Health & Ageing 2011) which had operated since 1992 to provide packages of community aged care services for frail older adults with complex needs who wished to remain living at home.

The new program maintains the objective of enabling older adults to live at home as independently and as long as possible. Consumer Directed Care has been embedded as the delivery model and emphasises consumer choice of services through collaborative care planning, the option of self-directed or provider-managed services, and individual budgets.

The previous Community Aged Care Package Program allocated packages at three levels according to assessed need, ranging from Community Aged Care Packages (CACP) at the lowest level through Extended Aged Care at Home (EACH) to Extended Aged Care at Home – Dementia (EACHD). These were replaced by four levels of Home Care Package:

- Level 1 to support basic care needs
- Level 2 to support low level care needs
- Level 3 to support intermediate care needs
- Level 4 to support high care needs (DSS 2014).

Under the previous program, service providers tendered for packages through Aged Care Approvals Rounds (ACAR) and received block funding to manage a specified number of active packages. This enabled some flexibility to make minor adjustments between clients to meet their actual care needs. Under the Home Care Packages

Programme, this flexibility has been lost as government subsidies are now paid to service providers as individual allocations to be used entirely by the consumer.

In the 2015 federal Budget, further changes were announced which abolished the Aged Care Approvals Round from 2016 (Commonwealth of Australia 2015). From February 2017 Home Care Package funding will be allocated to the individual older adult, who will be responsible for choosing their service provider. Providers will continue to manage the packaged funds on behalf of consumers and to assist in planning and organising services and activities. Packages will be portable between providers.

Four factors impact on the actual amount of subsidy available to consumers to purchase services. They are:

- the level of care need assessed by Aged Care Assessment Team (ACAT, or ACAS In Victoria)
- eligibility for additional supplements, also assessed by ACAT/ACAS
- the autonomy/self-management level chosen by the consumer
- the administration fee set by the provider, within the Home Care Package Guidelines.

Individual budgets

The total package together with any supplements for special needs such as dementia constitutes an individual budget to subsidise the cost of services. While consumers choose the services on which to spend their funds in accordance with their individual plans, Home Care Packages providers act as bankers, paying for services out of individual package allocations and issuing each consumer with a monthly financial statement. Consumers are able to accumulate funds towards anticipated future costs of services as their needs change.

Consumer contributions

Since 1 July 2014 the government has required CDC consumers to make an income-tested contribution to the cost of their home care package (DSS 2015b). Previously, this could be applied at the service provider's discretion. The following fees apply:

- All consumers pay a basic daily fee. The government-recommended fee is up to 17.5% of the single full rate Age Pension. Providers have discretion regarding the amount charged. It is very rare for BSL to charge the full 17.5%.
- Consumers whose annual income is above the Age Pension rate must pay an additional income-tested care fee. Service providers have no discretion over this amount, which is calculated by the Department of Human Services (DHS).
- Consumers may also make 'top up' contributions to their packages from their own financial resources if they choose, to cover costs of additional services.

Foundational principles of BSL aged services

All BSL aged services including the provision of Home Care Packages are predicated on the philosophy and principles of the capability approach (Sen 1999; Nussbaum 2011). The capability approach was originated by Amartya Sen, Nobel Prize – winning economist, as a way of better understanding how to recognise and address disadvantage. According to Sen, capabilities are the opportunities a person has to live a life they have reason to value. The most important elements of the capability approach are:

- opportunity: to be and do what you value
- choice: having multiple opportunities to choose from
- agency: to decide what’s best for you
- freedom: to live in an enabling environment.

Drawing on previous research into what BSL aged services users value in life and the BSL Aged Services Capabilities Framework (Kimberley, Gruhn & Huggins 2011), a BSL aged services pilot team created an approach to service delivery that shifted the emphasis from care as an end in itself to the understanding that ‘Care is a tool for living’.

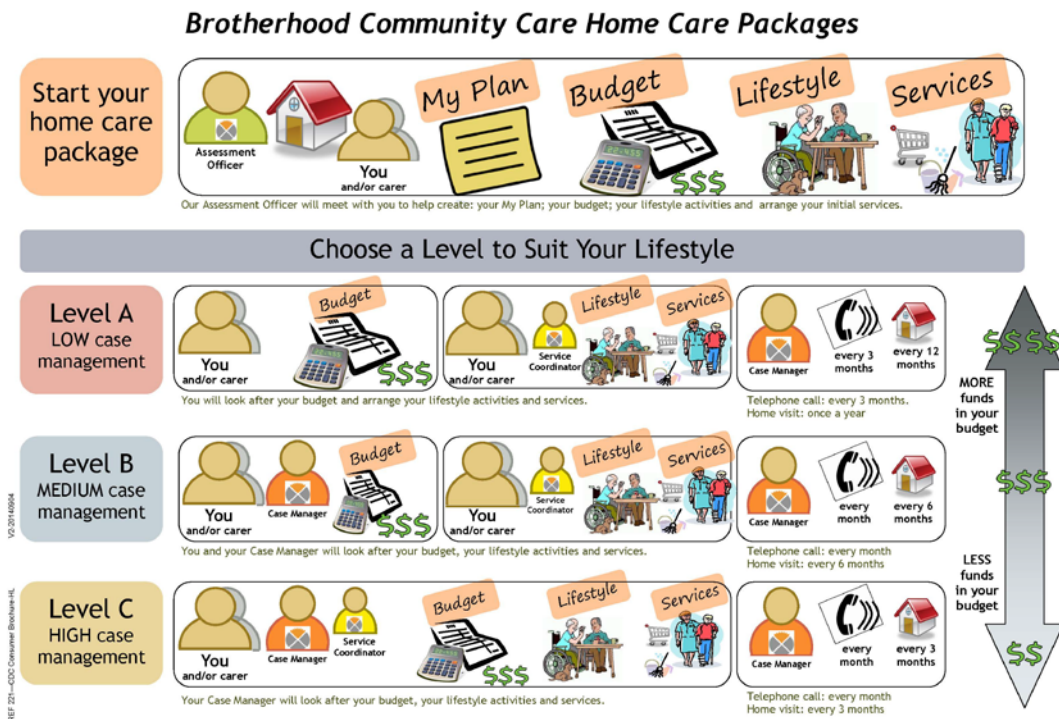
This work led to a new model for the co-production of an individual ‘MyPlan’ (care plan) by each service user, in dialogue with their case manager. Each plan is built on the individual’s life story, their values and what gives meaning to their life. Their aspirations are reflected in the possibilities open to them and an action plan built on their choices of Home Support services and activities to achieve their own particular vision of ‘a life of value’. The model is underpinned by a purpose-designed professional development program which has been delivered to all staff throughout BSL aged services.

In theory, the capability approach is compatible with CDC provided that the desired opportunities, choices, agency and freedom are live options. BSL aged services aim to make them so. However, despite its expressed intentions, the Home Care Package Programme may well prove to act both to free and to constrain.

BSL Home Care Packages

By mid 2015, BSL provided 586 Home Care Packages in the north-western and southern regions of greater Melbourne. Its model for the CDC approach to delivery offers every aged care consumer a wide range of service options and a choice of autonomy level (see Figure1). Case managers support consumers to build capabilities.

Figure 1 Infographic outlining BSL arrangements for Home Care Packages



Autonomy levels

Developed by the BSL community care team out of their experience with both the PACS project and the government-sponsored pilot programs, the BSL model offers a choice of three levels of autonomy, which define the amount of consumer self-management. Since case management must now be ‘purchased’ from package funding, the level of autonomy also influences the amount of money available to purchase services—that is, the more case management time that is purchased, the less remains for services and activities.

Autonomy Level A is suitable for consumers who require the least case management. They pay for the minimum amount of case management time, but can purchase additional case management services if needed and if their budget permits.

Autonomy level B is suitable for consumers who can self-manage some aspects of their package but still need some case manager support. As a result, these consumers pay for more case management time those at autonomy Level A.

Autonomy Level C consumers are those who are least able to manage their own packages and therefore require the most extensive case manager assistance.

Home care package subsidy

The BSL model opted to manage packages for consumers assessed as having Level 2 and Level 4 care needs.

BSL Home Care Packages consumer profile

As an organisation dedicated to ‘an Australia free of poverty’, BSL gives preference to older Australians on low incomes, many of whom experience multiple disadvantage including chronic health conditions and social isolation. Of the 586 BSL Home Care Package consumers, 15% are aged under 70 years, 35% are aged 70–79 years, 40% aged 80–89 years and 15% aged 90 years or more.

The staffing model

To accommodate the CDC approach to Home Care Packages, the staffing structure was reformed to include two new job roles in addition to case managers. The positions of Assessment Officer and Service Coordinator were introduced to take over the administration of activities and Home Support services chosen by consumers, so case managers could spend less time on administrative matters and more time on direct case management responsibilities such as developing and monitoring individual MyPlans.

BSL Home Care Package team

The Assessment Officer is the first Home Care Package team member to have contact with prospective new consumers, carers and families. They arrange and attend consumer assessments, introduce CDC and the BSL model, compile initial paperwork and then hand the consumer over to one of the 26 case managers. This ensures consistent messages to new consumers and uniform, accurate paperwork. These activities were previously the responsibility of each case manager.

A consumer next meets their allocated case manager whose role is to collaborate with them to design their package and agree on their capacity to self manage. This entails using the BSL Enhancing Capabilities approach to develop a care plan (MyPlan) that articulates the consumer’s aspirations for living a life that they value, the relevant goals, the available budget, the appropriate level of autonomy and an action plan with a service schedule. Case managers provide support, information and referrals and monitor the quality of service delivery and consumer wellbeing, in a way that optimises the consumer’s capabilities and opportunities to live a meaningful and fulfilling life of their choosing.

The Service Coordinator is the third member in the chain of consumer contacts. Once a consumer’s autonomy level and budget have been agreed and initial activities and home care services organised, the Service Coordinator is responsible for liaising with consumers, case managers and direct care service providers around scheduling and monitoring services and activities, keeping consumer records up to date and related administrative tasks. The consumer’s autonomy level influences the extent of the Service Coordinator’s administrative input.

2 Research design

The purpose of the evaluation of the implementation of Consumer Directed Care at the Brotherhood of St Laurence was to document the impacts on community aged care staff and consumers and the future organisational structure. To assist the evaluation an advisory group was established, comprising BSL Community Aged Care (CAC) senior managers, program managers and senior case managers.

This report focuses on the evaluation of the experiences of existing consumers as they transitioned to the new service delivery model and of new consumers who experienced it for the first time.

The evaluation, conducted from May 2014 to July 2015, used a qualitative approach to gather information from consumer interviews, consumer forums and two focus groups. In consultation with the advisory group, the evaluators identified the desired outcomes and priorities for BSL clients receiving services under the new CDC guidelines, and devised a framework for the interviews and the main evaluation report.

The study explored:

- how well consumers understood the elements of Consumer Directed Care
- how well they understood the new case management arrangements under the BSL model
- how they felt about the information provided to them
- what changes they had experienced to the services delivered and activities they accessed because of the new arrangements
- their attitudes to and acceptance of the new budget arrangements
- and the introduction of monthly financial statements.

Research method

Action research

An action research approach was employed which allowed the evaluation advisory group to reflect on the impact of the new delivery model on consumers as it was implemented. This cycle of observation, reflection, planning and action ensured collaboration between the evaluators and the advisory group. Scheduling a project evaluation alongside its implementation contributes to continuous improvement, a major factor in quality assurance. In this evaluation, through this process areas of improvement and potential concern were identified and acted on where appropriate.

Recruitment of research participants

A matrix was constructed to ensure that research participants represented a cross-section of all BSL consumers, in terms of package level, autonomy level, sex, living alone/living with others and having/not having a carer.

Retirement and Ageing Services staff assisted the researchers with recruitment. Case managers were provided with the sampling matrix, contacted consumers and carers and arranged interviews. This method protects clients' privacy as no information is provided to the researchers until clients indicate their willingness to participate. The researchers then visited the interviewees in their homes. Informed consent was confirmed by the researchers at the time of interview.

Individual interviews

Thirty-one consumers and/or carers were interviewed in September–October 2014. Another 14 were interviewed in June 2015, and 10 of the first group were re-interviewed at that time. Their circumstances were diverse: for example living alone or in couples, with or without full-time or part-time informal carers. There were 28 female and 17 male interviewees. Individuals had been receiving their Home Care Package for between 1 and 12 months: the majority were existing BSL clients who had transitioned to CDC, while the remainder had commenced with BSL under the CDC arrangements. The consumers interviewed were receiving Level 2 or Level 4 Packages and represented all three levels of autonomy.

Table 1 Consumers interviewed, by level of package and self-management

Time of interview	Level 2			Level 4		
	A	B	C	A	B	C
Round 1 only	1	9	4	2	5	0
Round 2 only	1	7	4	1	1	0
Both Rounds 1 & 2	2	0	2	1	4	1
Total	4	16	10	4	10	1

Consumer forums and focus groups

Informal consumer forums were held by BSL Community Aged Care to advise on the design of the BSL CDC model and provide feedback about its implementation. Over 2014–15, 99 consumers and 24 carers attended.

Two focus groups were also organised by BSL Community Aged Care and were facilitated by external personnel, who collated the consumer views and presented feedback. Each of the focus groups (2014 and 2015) was attended by 5 consumers and 2 carers. Outcomes of forums and focus groups were shared with the evaluation team.

3 Findings

Consumer response to CDC

Consumer understanding of CDC

While some interviewees clearly understood from an early stage the main elements of CDC, such as the way funding is allocated, responsibility for budget management, the opportunity to organise activities and Home Support services for themselves and the possible impact on the scope of services or activities they could afford within their individual budget, others did not. Despite frequent explanation by case managers and written information in a variety of formats, about half of the 45 interviewees said they were still confused about the term 'consumer directed care'.

Nevertheless, many showed that they understood the core elements once they were asked about the services they received.

Consumer responses to information provided

In its efforts to be transparent, initially BSL provided consumers with copious information about CDC. This proved overwhelming for most consumers and carers. Several reported just reading the bits they felt were relevant or putting it away without reading it. One consumer with very low literacy said that she would 'rather have other people tell me and help me, because I can't do it'. Carers were more likely to read the information supplied and keep it for future reference:

I've got a big book there, so anything I need to know, it's right behind me, it stays there all the time.

Yes, I have read it. Took a bit of ploughing through, but I thought I'd better [read it].

At the consumer forum in April 2015 consumers and carers suggested simplifying the language, reformatting information for those with limited literacy or vision impairment and translating the text into community languages. The infographic explanation (Figure 1) proved popular among consumers.

Consumer understanding of CDC at BSL

Consumer self-management and engagement between consumers and case managers are important elements in the new Programme guidelines, as are individual budgets. These were explained to each consumer and carer by the case manager as they worked together to plan services and activities. By the end of the pilot, most consumers and carers interviewed reported some understanding of the three autonomy levels of the BSL model. Overall, carers or family members had a better understanding than consumers.

There were a few areas, however, where some interviewees expressed confusion:

- *choice of autonomy level*

About half of all interviewees said that they decided on their autonomy level in collaboration with their case manager:

It was about 50/50 between [case manager] and I. I had a lot of input but also I trusted them to know what I could do with my limitations.

About a quarter said that the case manager decided for them or that they 'went along' with the case manager's decision because they trusted their judgement of their capacity to manage. A similar number were unable to remember discussing their autonomy level. One carer said she decided for herself even though the case manager was initially reluctant to accept her choice.

- *taking responsibility for self-management*

Some interviewees were well informed about the role of the Service Coordinator:

Yes, she helps with queries [on things like financial statements]. In fact, I rang her yesterday with a question.

They've got the girls on the phones now that you can just ring in, or I'll send them an email.

However nearly half the interviewees were confused about the role:

I would have understood what she was telling me at the time but unless it was anything to change my way of life in any way, it goes in and then I forget it.

Many interviewees were also confused about the number of case manager visits and phone calls they were entitled to at their autonomy level. Some of these were existing consumers who had selected the highest level. This confusion was also raised at the consumer forums.

Well, they used to come every three months, now they're telling me they're coming once a year.

Me and [case manager] are together regularly, it's sort of ... she comes out six or eight times a year.

A significant number of interviewees on the higher autonomy levels resisted following the procedures about which staff member to contact for which purpose. While a few said they deliberately chose to organise their services through their case manager, others, especially some who live alone, reported not remembering having the information, not understanding it or feeling overwhelmed and needing reassurance. Since many consumers have close working relationships with their case managers stretching back over many years, some case managers suggested that the comfort of familiarity might also be in play:

A lot of older people feel more comfortable speaking with someone that they have a relationship with even if it's just for a few minutes on the phone because that few minutes, for some people it's some contact, a bit of a welfare check, a bit of a chat, rather than just a clinical phone call to a Service Coordinator whom they've never met or seen and don't have a relationship with.

Individualised budgets and monthly financial statements

Most consumers and carers had a good understanding of the concept of the individual budget, with one describing it as 'a bank account with money in it for things I need, but that someone else looks after'. Most consumers and carers were pleased to receive a monthly statement and reported that they felt more 'secure' knowing their budget position, 'what I've spent and what I haven't spent'.

It helps me to know where I am at, it's better for me, because I can't do a lot with money now. I had a stroke and the old noggin doesn't hold a lot of information.

Some consumers were indifferent to receiving financial statements because 'if something was wrong the case manager or someone would ring and say'. Three consumers disliked receiving them as they were a 'waste of paper' or 'too complicated'. Just under a quarter of consumers found the statements difficult to understand, with one consumer unable to read the statement at all and another still 'bewildered' even after several explanations.

Nonetheless, most consumers appeared to understand their budget position in terms of whether they were 'in budget' or 'over budget', through information provided by the case manager.

I know what is in the budget and I know roughly what it costs.

Most of the 'transitioned' consumers interviewed reported that there had been no change to their services due to budget restrictions, and some reported a budget surplus. Some had chosen to make minor changes to their services to build up a surplus for future services or equipment as their needs change. Only one carer reported significant cutbacks due to budget restrictions, in the form of reduced in-home respite which under previous block funding had been subsidised by BSL.

Choice and control

As consumers' understanding of the individualised budget and opportunities for choice and control over their services increased, many began to take the initiative in spending their funds in line with the health and wellbeing goals outlined in their MyPlan.

Many consumers appreciated the flexibility to coordinate their own services, including being able to organise them quickly in response to an urgent need, or to ask care attendants to undertake tasks as needed, rather than a fixed set of tasks for each visit. Having a say gave many consumers a sense of independence and confidence in their own ability:

It's empowering to be able to do your own [organising] and not rely on phoning and asking 'Can I do this?' I think that's a bit degrading when you have to beg for something.

It gives you confidence that you are still 'with it'. Even though I'm fairly young, having lots of medical problems it's nice to know that you can still run your own affairs and feel independent. It's the independence.

Some consumers had deliberately accumulated funds for the future in anticipation of their increasing needs as their physical or medical conditions change:

I've been saving up [funds from my package] to get a manual wheelchair for the house. I've recently bought a proper shower stool [with package funds].

Some had reduced the frequency of some services, or sought additional informal support from family or friends. Others had rearranged or reduced existing Home Support services to retain activities they particularly enjoyed, such as regularly visiting a garden nursery, or to manage an overstretched budget by purchasing an iPad to shop on line in lieu of paying for shopping assistance.

Most of the 10 consumers who were re-interviewed in the second round had developed a better understanding of their CDC package. They were less concerned about the intricacies of CDC than about whether or not their services were of a good standard and delivered in a way that suited them.

The majority of consumers interviewed were satisfied with the services and the level and quality of case management they received. For almost all, their relationship with the case manager was highly valued. Participants in the consumer forums who had transitioned to CDC indicated that overall their experience of the new arrangements had been positive, that they were 'learning a lot' and that they believed their choice of services and activities had increased.

Utilising technology to manage packages

BSL is encouraging consumers to use email and the internet to contact Home Support service providers, service coordinators and case managers and find information they need. This is part of an overall effort to increase their digital skills in an online society; also email requires less staff time than telephone calls and consequently reduces the cost to consumers. However, only about 7% of consumers or carers currently use this method of communication.

I use the internet to contact my case manager [because I understand their workloads]. So instead of me trying to ring and getting frustrated when I can't get through, I send an email.

I use the internet to send off my expenses at the end of the month. It's how I communicate with [the Service Coordinator].

While half of the interviewees said that they used, or knew how to use, a computer or an iPad, only a quarter said that they would like to use technology to contact service providers or BSL in the future. For many it was a 'daunting' prospect and they 'don't do the computer thing very well'. Most reported that they preferred to use the telephone to make contact.

The majority of consumers and carers at the consumer forums reported that they did not have access to the internet, did not have a computer at home, were not IT literate or thought that they would not be able to acquire the skills, even if training was offered. They indicated that, as a result, information provided via emails or websites (such as My Aged Care and Centrelink) were not accessible to them.

Social activities and the BSL Social Inclusion Programme

For many years prior to the introduction of CDC, thanks to block funding, BSL clients had been able to attend activities subsidised through the Social Inclusion Programme (SIP). These were especially popular among those who were otherwise socially isolated. The program had provided a diverse range of low-cost options including exercise classes, painting/craft classes, theatre outings, regular lunch and afternoon tea groups, cultural activities and outings, dementia-specific activities and an annual Christmas party.

However, with the introduction of fee for service as a result of individualised budgets, only half of those interviewed who had attended SIP activities said that they would probably continue to attend. Two said that they would use their own or their families' resources to pay for the activities, with others saying that they would reduce the number of activities, be more selective about which activities they attended, or would 'play it by ear' or wait to see 'how close to the wind [I am] with my budget' and only go if they could afford it. Only one consumer said they would cut back on personal care or domestic services to attend.

New and transitioning consumers

There was some variation in consumer response to CDC mainly depending on whether they were new or existing clients.

Transitioning consumers

The shift to individualised budgets meant that service providers could no longer reallocate unspent funds to consumers with higher or non-standard needs. Consumers who were now 'over budget' had to prioritise and reorganise their services to fit within their individual subsidy. However, the small number who did need to reduce services reported that the quality and adequacy of their care were not compromised. With the capabilities approach underpinning BSL aged care services, consumers had already been provided with spending choices limited only by program guidelines, congruence with their care plans and their budget. This meant they already accessed a diverse range of services, support and activities that in many other care agencies would be considered 'non-standard' and unavailable.

New consumers

As the KPMG evaluations (2015, 2012) also found, some new consumers also experienced challenges with CDC. For those who had recently experienced a health crisis, such as hospitalisation following a fall, or who had little experience of formal services prior to receiving their home care package, it could be daunting to assimilate new and complex information about services and funding, negotiate the choices for self-management, develop a plan, prioritise services to fit their budget and grapple with monthly financial statements. As a result some preferred a case manager to take these responsibilities until their situation became clear.

For new consumers with assets or income greater than their family home and the Age Pension, the DHS financial assessment sometimes resulted in a level of required financial contribution to services that was a shock.

Enablers and barriers

The consumers experiencing the fewest issues with the CDC system were, in the main:

- consumers whose needs were met within their budget
- new consumers who had only known the individual budget CDC model
- consumers who had some personal financial resources or who could access support from family members or other networks to supplement the package subsidy
- consumers who had a carer or who could fully manage the package (Level A), releasing more funding for services and activities
- consumers willing to make changes and to work with their case manager to do this.

The consumers who were more likely to experience difficulty with or were impacted more severely by the CDC system were, in the main:

- existing consumers who were over budget, mostly as a result of their complex care needs and medical conditions
- consumers with low levels of literacy, numeracy and especially financial literacy
- consumers who were financially disadvantaged and lacked personal funds or a support network to cover the full range of their care requirements
- consumers who had no carer or who had cognitive impairment and did not have the capacity to self-manage and therefore had to allocate a larger portion of their subsidy to case management fees
- consumers who were resistant to the change and not prepared to work with their case manager to manage their budget.

4 Discussion

In many respects the findings of this evaluation are consistent with those of the KPMG evaluation of the pilot program commissioned by the Australian Government Department of Health (KPMG 2015) and the PACS evaluation (Ottmann, Laragy & Allen 2012), the only other published evaluations of self-directed care in Australia. All found that, for the majority of consumers, consumer directed care had many positive outcomes such as, to use the PACS phraseology, 'more say', 'more flexibility', 'more choice and control', a 'better handle on finances' and increased capacity. Many consumers were delighted to be self-managing.

However a wide variety of consumers displayed less interest and satisfaction with CDC. For example, similar to the KPMG (2015) findings, some consumers and carers were not interested in their individual budgets or found them complex or confusing and preferred to hand responsibility to case managers. Most of those who were interested were keen to build a surplus to plan for additional services such as respite or more expensive equipment (KPMG 2015). However, in staff focus group discussions some BSL case managers expressed concern that some consumers might be reducing services to 'save money'. One reported that although the consumer had a surplus, the carer 'refuses to spend the money despite struggling' and is 'waiting until things get really bad'. Building a surplus may be prudent if judiciously managed, but not at the risk of poor health and wellbeing which may lead to more complex conditions.

BSL service users had a better understanding than those surveyed by KPMG of the opportunities inherent in the wide range of services and activities that BSL enabled them to purchase; and many used their funds for very individual pursuits rather than 'standard' choices offered by some providers (KPMG 2015, p. 45). They appreciated the commitment of their case managers to working with them to develop individual plans that holistically enhanced their lives. Time spent with their case managers was highly valued overall but particularly by those who were isolated or disadvantaged by poverty.

Like consumers in the KPMG evaluation (2015), some existing BSL service users moving to CDC had to find creative ways to reduce the costs of their services and activities, preferably without compromising their quality of life. For some this meant seeking assistance from family members to help administer their package, thereby saving case management costs. Others with fewer expenses for items such as medications chose to pay for some services themselves.

Beyond these matters, this evaluation made some significant new findings relating to the capacity of many consumers to manage CDC and the impact of CDC on social participation.

Capacity to manage CDC packages

The CDC approach to home care package management is complex and, as the findings indicate, many consumers found it confusing. They had to develop a fuller understanding of their individual package than had been required under the previous community aged care program. For existing consumers this meant thinking about many aspects of their package in new ways, including who would be responsible for managing their individual budget and organising their services. The majority of BSL home care consumers experience a range of disadvantages and some lack the literacy, numeracy and other life skills to take control, make choices and manage the services and activities that would enhance their lives.

Literacy and life skills

Managing a home care package requires competency and confidence in a variety of 'literacies'. As pointed out in the Adult Literacy and Lifeskills Survey (ALLS), these are 'important for an individual's ability to participate fully in modern society' (ABS 2008, p. 4).

ALLS measures five types of literacy and life skills: prose literacy, document literacy, numeracy, health literacy, and problem solving—that is, goal-directed thinking and action in situations for which no routine solution is available (ABS 2008, p. 4). On each of these, more than 70 per cent of Australians aged 65–74 are rated below Level 3, the 'minimum required for individuals to meet the complex demands of everyday life and work in the emerging knowledge-based economy' (OECD/Statistics Canada 2005).

This data may help to explain why so many BSL consumers were unclear about the details of CDC, found the information overwhelming, and continued to seek frequent support and reassurance from their case manager.

Internet access and digital literacy

Older adults are reported as having the lowest levels of digital competence of all consumers; and this is cited as a key factor for older adults' low digital participation (Warburton, Cowan & Bathgate 2013). Digital competence is often associated with other competencies such as information literacy, media literacy, visual literacy and communication literacy. Certainly, many older users of Home Care Packages struggle to access information or communicate online (De George-Walker & Tyler 2014).

ABS data (2016) shows that in Australia older persons aged 65 or over have the lowest rate of internet use. For example, in 2014–15, only 51% of this age-group were internet users, with 70% of users spending between one and seven hours a week online.

Lack of digital competence can be compounded by lack of financial resources. In 2014–15, 22% of individuals with a personal income below \$40,000 did not have an internet connection (ABS 2016). Most BSL Home Care Package consumers fall below this income level.

Given the low level of internet access and use by older Australians, especially those on low incomes (Wise 2013), it is not surprising that very few BSL consumers of Home Care Packages used email to contact the BSL service. While BSL can manage this in the short term, it will be increasingly problematic, in that cost savings for both consumers and BSL cannot be made. Moreover, with the internet becoming the primary mode for communicating with many government agencies, including My Aged Care and Centrelink, BSL service users are already disadvantaged. While consumers can spend some of their Home Care Package funds on internet connection and hardware, with only about 7 per cent currently using the internet, it may take some time for this proportion to reach a significant level.

It is to be hoped that the development of the Australian Digital Inclusion Index (Swinburne University 2016) will pave the way for digital policies and resources that actively enable the economic, social and cultural participation of older, more disadvantaged Australians.

Social engagement

One of the disappointing impacts of CDC was the reduced participation of the BSL community care clients in the BSL Social Inclusion Programme (SIP) which had been designed for service users who were socially isolated. Under the block funding model participation had been subsidised but with the full cost now having to be met from individual packages, many consumers have decided they cannot afford to participate. The consequences may be serious, especially for consumers with mobility limitations and those who live far from family and friends. Social isolation has been shown to constitute a major risk factor for health, rivalling well-established risk factors such as cigarette smoking, blood pressure, blood lipids, obesity and physical inactivity (House, Landis & Umberson 1988); and social networks of discretionary relationships contribute to longer life expectancy among older Australians (Andrews et al. 2005; Due, Holstein & Lund 1999). Despite social connectedness often being given low priority by aged care services, Brotherhood aged services have always regarded it as essential to wellbeing and quality of life. The previous community aged care model had allowed some flexibility to providers to vary the level of support to individuals in line with actual needs and to underwrite programs such as SIP for the common good. However, since individual budgets, consumers need to cover the full cost not only of the social activity but also of attendant care and transport. For many consumers this makes the cost prohibitive even for a simple morning coffee. The impact is magnified for those who are unable to self-manage their packages and therefore incur higher management costs.

Consumer directed care – some policy issues

With limited experience so far in Australia, it is useful to consider the Australian model of consumer directed care in relation to its UK counterpart. However there are some important differences. For example, the United Kingdom has adopted a model in which funds are not only allocated to individual service users but preferably paid direct into

their bank accounts so that they can take full responsibility for their services such as financial management (including payment of invoices), engagement of service providers, case management if required and the legal responsibilities associated with employing care workers of their choice, including family members. In Australia, the level of governance is much more prescriptive and consumers are less exposed to risk than their UK counterparts. While funds are allocated to individual Australian consumers who, in consultation with providers, choose how they are spent, providers retain responsibility to act as bankers and to collaboratively advise, plan and budget. Moreover Home Support workers cannot be employed directly by consumers but must be registered, approved and contracted or employed by Home Care Package providers. Thus, the extent of self-management is more limited than in the United Kingdom. Nevertheless, there are some important parallels between the two different systems of self-directed care in their consequences for older adults.

The personalisation of care through adequately funded and regulated human services markets has been shown to offer significant benefits for some service users, relative to conventional, centralised or standardised care provision. It has the potential to give people increased choice and control and tangibly improve their quality of life, providing that the change from conventional to personalised care is well managed, and users have access to appropriate support and information (Rabiee, Moran & Glendinning 2009).

However, there is an emerging consensus that personalised care is less effective for older people (Glendinning et al. 2008). As UK studies have found, individual budgets carry many risks. For example, many older adults did not want the hassle of self-management and experienced deep anxiety and stress about managing their care arrangements which nudged out any positive feelings about greater control or flexibility. This was particularly pronounced among those living with dementia (Baxter, Rabiee & Glendinning 2013). Having responsibility for all financial aspects of care can have a deleterious impact on mental health while delivering only marginal benefits in terms of choice and control (Borgstrom & Walter 2015) and can increase the risk of abuse (Manthorpe & Samsi 2013). The shift of the administrative and management tasks and costs formerly borne by providers onto individual service users and their families also imposes a substantial burden that can cause anxiety (Larkin and Mitchell 2015; Rabiee, Moran & Glendinning 2009; Moran et al. 2012). It may tacitly constrain the choices of family carers (Larkin & Mitchell 2015) as they face the challenges of managing an individual budget on top of their caring, family and employment responsibilities.

Conclusion

While the KPMG researchers may be justified in asserting that ‘just as it takes time for many consumers to be comfortable in asserting and exercising some control, the transition from a service provider/care recipient relationship approach to care will also take time’ (KPMG 2015, p. 46), there will also always be some consumers, like many of the BSL clients, who are unable to retain and understand complex information.

Absorbing and understanding the information required to manage one's home care package, individual budget and monthly financial statement, negotiating choices for self-management and accepting the contingent responsibilities will always be problematic for many service users who experience social and economic disadvantage.

CDC may yield benefits for capable adults, *provided* they have the means to exercise meaningful choice and control. With adequate support, it has the potential to empower service users and fits well with the capabilities approach advocated by BSL. However, to avoid increasing the burden of risk for consumers, carers and their families, CDC must be accompanied by practical support such as administrative, financial and professional services to enable positive risk taking and to safeguard against abuse, as well as continued investment in appropriate governance and regulation.

It is early days for CDC in Australia and, to date, the program assumes the availability of a substantial level of support for consumers, which is manifested in the BSL CDC model. However, the Harper Competition Policy Review signals the intention to increase individualisation:

Putting users in control of the human services they access—either through direct payments, personal budgets, entitlements or choice—drives service providers to become more responsive to individual requirements. (Harper et al. 2015, p.35)

The next stages in the Australian Government's reforms to aged care services point in this direction. From February 2017 Home Care Packages will be allocated directly to consumers, who will select the provider they want to assist them to manage their package. They will have the right to change provider if they think they will be better served by doing so.

Whether aged care reform in Australia will go so far as to enable consumers to 'cash out' their care package funds, manage all banking and payment for services and take responsibility for employment of service workers, as is the case in the United Kingdom, remains to be seen. While this would maximise flexibility for the more capable consumers, it is likely to increase opportunities for elder abuse and impose an unmanageable burden on those who are already struggling.

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