Self-management in Consumer Directed Care (CDC) programs: literature review

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Introduction

This literature review provides an overview of consumer directed care (CDC) programs and focuses on service system design and implementation strategies shown to contribute to successful self-management and positive outcomes. The purpose of this review is to inform the development, implementation and evaluation of the *Increasing Self-management in Home Care Project* being conducted by COTA Australia (COTA Australia, 2019). The project was funded by the Australian Government, Department of Health under the *Dementia and Aged Care Services Fund: Developments that support innovation in aged care.* This literature review will contribute to the development of two toolkits – one to assist service providers implement self-management, and another for consumers who self-manage.

The *Living Longer, Living Better, Aged Care Act 2013* (Commonwealth of Australia, 2013) requires all Australian aged home care packages to be delivered as 'consumer directed care' (CDC) (My Aged Care, 2017). While all packages have to be supervised by a registered aged care service, people can choose their provider. Service providers are expected to include older people as active agents in decisions about their health, lifestyle and daily living requirements. The 2018 *Aged Care Quality Standards* (Australian Aged Care Quality Agency, 2018) reinforce these principles. Currently self-management is not a widespread option. This project will provide evidence regarding factors that promote or constrain the effectiveness of self-management.

This literature review includes seminal CDC papers. Many CDC papers have been published across the globe and this review has selected papers most relevant to the COTA Australia self-management trial. The term 'consumer' refers to both the older person and their carer representative them who manages the budget. Distinctions between the two are made when referring to their separate needs and opinions.

Consumer Directed Care

The introduction of CDC is part of an international trend giving consumers more choice and control over their government allocated packages. CDC programs give consumers choice over the level of responsibility they want to take for managing their package. Consumers can manage all or part of their package, or have an agency undertake all management responsibilities and organise their services and manage their finances. Most CDC programs allow consumers to purchase supports and services from the open market and not be restricted to registered aged care service providers as long as the purchases are consistent with an agreed plan. The Australian Government says that:

> *CDC gives you flexibility and choice in the delivery of your care and services under your home care package. It gives you more control in determining the types of care and services you receive, how they are delivered, by whom and when.*
>
> *From 1 July 2015, all home care packages have been required to be delivered on a CDC basis. Home care package providers must work in partnership with you to design and deliver services that meet your goals and assessed care needs as determined by the Aged Care Assessment Team (ACAT).* (Australian Government, 2017:1)

CDC programs were pioneered in the disability field and various names have been used across disability and aged care. The United Kingdom (UK) used *individual funding, personalisation*, *personal budgets* and *direct payments* (Hamilton et al., 2016); some European countries used *cash-for-care* (Da Roit & Le Bihan, 2010); parts of the United States (US) and Canada used *Cash & Counseling* (Robert Wood Johnson Foundation, 2015), and *direct funding* (Hutchison, Lord, & Salisbury, 2006). The term *self-direction* is now widely used. While Australia maintains separate programs for aged care and disability support, in the UK and Northern America programs usually include both groups of people.

There is wide variation across programs regarding assessment policies, allocation of funds, who holds the funds, accountability requirements, and the degree of choice and control afforded to consumers. An analysis of Australian CDC disability programs identified differences in all these dimensions, with some allowing consumers to recruit and employ their support workers while others did not (Purcal, Fisher, & Laragy, 2014). It is important to be aware of the differences between programs when comparing outcomes.The research findings summarised below attempt to identify the key program design features that lead to positive outcomes.

United States

The US *Cash & Counseling* program (later rename *Participant-Directed Support*) supported people of all ages and types of impairments from 1996 to 2013 to 'self-direct' their US Medicaid funds (Robert Wood Johnson Foundation, 2015). The initial 'demonstration' project commenced in three states and expanded to 15 states. While state programs varied in structure, they all aimed to support people to remain living independently at home in the community. Most programs provided free-of-charge support for people as required. The program supported 13,500 people with chronic impairments who qualified for support. The Robert Wood Johnson Foundation financed the program's implementation and evaluation. A series of evaluations were conducted using randomised trial and control groups. The outcomes for CDC participants who self-managed were compared with those receiving traditional agency managed support. Quantitative, demographic and outcome data were collected from all states, plus in-depth qualitative interview data from some states. The *Cash & Counseling* program has the most thorough evaluations of any CDC program identified in the literature search. The Robert Wood Johnson Foundation (2015) provided a summary of the outcomes from the CDC evaluations they sponsored:

- CDC consumers experienced better health outcomes and reduced unmet needs
- CDC consumers experienced better quality of life, as did their carers
- Medicaid personal care costs were somewhat higher, mainly because CDC consumers received more of the care they were authorized to receive, which previously had not been provided
- The increased costs were partially offset by cost savings in institutional and other long-term care
- Self-directed support programs do not cost more than traditional personal care programs if programs are carefully designed and monitored
- All states continued their participant-directed programs after the *Cash & Counseling* program ceased.

One *Cash & Counseling* evaluation was particularly relevant to the COTA Australia trial. The qualitative study in Arkansas interviewed older consumers who self-managed (San Antonio et al., 2010). There were no entry screening processes or exclusions, and everyone interested in self-managing was supported to do so. The majority of people chose to self-manage because they were dissatisfied with previous agency managed support. Agency support workers were often unreliable and restricted to performing a narrowly defined range of tasks. The program provided consultant support and a fiscal intermediary to manage the finances at no cost to the consumer. The consultants played a key role in providing information and advice, and monitoring the quality of care. The consumer's needs determined the level of support provided by consultant, and this was generally lower when family members were involved. Consumers recruited their own support workers, which could include family members. The evaluation found that having trustworthy support workers was especially important to older people who felt vulnerable with strangers. The study concluded that self-management is appropriate for a wide range of consumers as long as the necessary supports are provided.

Numerous peer reviewed articles have detailed the outcomes and challenges encountered in the *Cash & Counseling* program. The findings were predominately positive. O'Keeffe (2009) provided a summary of the processes found to produce positive outcomes:

- Involve consumers and all stakeholders in planning, designing, and implementing a new program
- Delineate roles clearly
- Develop a formal communication strategy to include all stakeholders
- Enlist the case manager's support as this cannot be taken for granted – changes in their role can result in opposition
- Spend time educating all stakeholders about the budget methodology
- Allow time to develop new financial management services as this is challenging.

The lessons learnt from implementing and evaluating *Cash & Counseling* programs are available in a handbook titled *Developing and Implementing Self-Direction Programs and*

Policies: A Handbook (Department of Health and Human Services, 2010). While much of this lengthy guide is US specific, sections relevant to Australia include the importance placed on including consumers in program design, implementation and evaluation of programs.

United Kingdom

CDC commenced in England in 2005 when 'adult social care' individual budgets were piloted and evaluated (Glendinning et al., 2008). The programs included people with disability and older people. Glendenning et al. evaluated the first pilot project (2008). Although this study is widely quoted, much of the data were collected early in the program when people were only beginning to use their personal budgets. Consequently, the reliability of the outcomes is questionable. The early findings showed that people welcomed the increased choice and control that individual budgets brought. However, the positive benefits of having greater control and flexibility were overridden by anxiety and stress about their care arrangements. Older adults had lower levels of psychological health and wellbeing and poorer health when they did not receive sufficient support.

When Glendenning's data regarding older people were analysed, the major concern of most older people was not having sufficient funds to meet their needs (Moran et al., 2013). Financial austerity cuts to public services resulted in individual budgets being cut, with funding provided for basic personal care but not for wider social supports. When concerns were expressed, it was not clear whether they expressed resulted from consumers using individual budgets or from reduced allocations. The study concluded that successful outcomes are dependent on the person being allocated sufficient resources to meet their personal care needs, having sufficient information and support to plan effectively, and having the ability to manage their budget. Caution needs to be taken when examining reported outcomes to determine if they resulted from self-management or from other factors such as receiving insufficient funds to meet basic personal care and social needs.

In Control is a UK not-for-profit organisation founded in 2003 to lobby for people with disability to live independently in the community using flexible personal budgets (In Control, 2016). Since then, it has expanded its remit to include older people. *In Control* aims to give people maximum choice and control over their allocated 'social care' supports. It works with governments, agencies, user-led organisations, commercial companies, and people and their families. *In Control* has contributed to service design and evaluations in a number of jurisdictions. For example, it played a leading role in developing the useful 2018 Scottish *Guide to making Self-Directed Support Work for Everyone* (Smith, Brown, & In Control Scotland, 2018).

One evaluation of personal budgets conducted by *In Control* soon after their introduction found modest outcome improvements compared to previous block funded arrangements (Waters, 2010). This study did not distinguish between people who self-managed and those who were agency managed. This early evaluation found:

- 66% of people reported having more control over their support and 68% had improved quality of life

- 58% of people reported spending more time with people they wanted to be with, 58% took a more active role in their local community, 55% felt that they were supported with more dignity, and 51% felt they had better health
- 58% and 52% of people respectively reported no change with regard to feeling safe or their standard of living
- Less than 10% of people reported life getting worse in any way.

In Control worked with Lancaster University and developed the *Personal Outcomes Evaluation Tool* (POET) (Think Local Act Personal, In Control, & Lancaster University, 2014). This tool was used in the study reported above, in a 2014 evaluation of people using personal budgets (ibid, 2014), and it is currently being used by local councils to gather national data from 'personal budget holders and carers across adult social care and health'. The 2014 outcome findings were more positive than those in 2010 reported above. This suggests that it takes time for personalisation practices to impact on outcomes. Key findings from the 2014 study were:

- The impact of personal budgets on people who need support and their family carers was mostly positive for all groups involved in the survey
- At least two thirds of respondents said their personal budget made things better or a lot better in 11 of the 15 areas recorded:
  - Dignity in support (82%)
  - Independence (78.9%)
  - Arranging support (79.9%)
  - Relationships with people paid to support them (75.9%)
  - Quality of life (81.4%)
  - Mental health (66%)
  - Control over life (70.6%)
  - Feeling safe (72.8%)
  - Family relationships (74.6%)
  - Paid relationships (67.8%)
  - Self-esteem (73.2%)
- A significant number of people found the process difficult, in particular negotiating the budget, planning, and choosing and accessing support
- People with learning disabilities and people with mental health difficulties were more likely to report difficulties
- Older people reported that having a personal budget made little difference.

The 2014 *In Control* study concluded that people who felt their views were included in assessments and planning were more likely to report positive outcomes when using a personal budget than those who felt excluded.

A separate UK study of older people using personal budgets was conducted by a consortium of universities (Woolham, Daly, Sparks, Ritters, & Steils, 2017). This used a series of quantitative measures to determine whether people 75 years and older who self-managed had better outcomes than those who were agency managed They found that people who self-managed appreciated the extra control they had, but there were no statistically

significant differences in outcomes between the self-managed and agency managed groups. With small budget allocations resulting from continuing financial austerity, they concluded that it may be necessary to consider some block funded services. This report was more sceptical of the benefits of self-managing budgets than were the *In Control* reports.

Australia

A review of the Australian literature on self-managed programs found three types of studies. These were studies that examined expectations of CDC prior to its commencement, transitioning to CDC, and CDC trial evaluations. The strongest evidence came from the trial evaluations.

Australian CDC trials

The literature search found evaluations of four Australian aged care CDC trials. All were conducted prior to CDC being mandated in 2015. The Victorian 2010-11 *People at Centre Stage* (PACS) program (Ottmann, Laragy, & Allen, 2012) was the earliest trial found. This was funded by an Australian government research grant, and used a co-production approach that involved consumers and service providers in developing the PACS model. Three service providers and 87 consumers conducted the trial. The evaluation found that consumers liked: i) being able to decide what supports to purchase; ii) having a wider range of options to choose from; iii) and being able to contact service providers directly rather than working through a case manager. By engaging with these activities consumers felt less lonely and more confident. Notably, negative outcomes were reported by eight consumers. They all missed case manager support, especially when they wanted help with managing support workers. Staff in the three agencies found the transition to the CDC model challenging as their roles and responsibilities changed markedly. They were expected to be more supportive and facilitative, and lost some authority and control (Laragy & Allen, 2015).

The Australian Government funded a second CDC trial called CHOICES (Ottmann, Millicer, & Bates, 2015). The trial was conducted during 2012-13 in Victoria, included staff and researchers who had been involved with the PACS trial, and focused on three diverse populations. This project used a co-production approach to refine the PACS CDC model and tested the model: in regional/ rural areas; with an Indigenous community; and with a Greek community. Seven aged care agencies and 195 consumers participated. The positive findings from the evaluation were that half the consumers reported a better understanding of their care package, most were more engaged in planning decisions, and allocated funds were used more flexibly. The challenges identified were that the different communities had different needs and expectations. In all communities, frail older people needed much support and assistance to manage their care arrangements.

The Brotherhood of St Laurence (BSL) in Victoria conducted a third CDC trial. BSL had participated in the PACS trial and subsequently involved consumers in refining their CDC model. A qualitative evaluation of the program was evaluated during 2014-15 by conducting interviews with 45 consumers (Simons, Kimberley, & McColl Jones, 2016). The findings showed that many consumers initially found the CDC model to be complex and confusing.

With support consumers learnt to use their funds flexibly over time, and they gained confidence in self-managing. Factors consumers particularly liked were: i) having monthly financial statements; ii) the flexibility to reorganise supports when circumstances changed, especially in times of crisis; and iii) the flexibility to direct support workers to undertake tasks as required and not follow a standard routine.

Service providers Avivo and Mercy Care conducted another CDC trial in Western Australian with aged care consumers who managed their Home and Community Care (HACC) packages. (Peterson & Buchanan, 2016. Unpublished). An evaluation using quantitative and qualitative measures was conducted during 2013 and involved 43 consumers and 12 staff. The positive findings were that scores on quality of life, self-efficacy and resilience generally increased, and there were fewer pressures on families. The challenges identified were providing the necessary information effectively; implementing policies consistently; recruiting suitable workers; and accessing appropriate services. These issues have been identified in many CDC evaluations.

CDC transitions

Four studies were found that reported on organisations transitioning to CDC. A national study was contacted by KPMG during 2014-15 (KPMG, 2015). At that time approximately 31% of aged home care packages were delivered using the CDC model. KPMG identified three types of service providers: 'early adopters or leaders'; 'proactive'; and 'reactive or resistant to change'. The findings showed a close correlation between the views of consumers and their service providers. When service providers were positive and enthusiastic, so were the clients, and the reverse also applied. KPMG concluded that service provider attitudes influence the views of consumers they support.

A second transition study was conducted in New South Wales during 2015 (Day et al., 2018), a third in South Australia and New South Wales (Gill, Bradley, Cameron, & Ratcliffe, 2018), and a fourth in Tasmania during 2015-16 (Orpin, King, & Boyer, 2016). The first, second and third studies reported similar findings. These found that: i) many consumers and staff had limited understanding of CDC; ii) both consumers and staff were fearful of transitioning to CDC; iii) few services were adjusting their service model to prepare for CDC; and iv) there was a need for further information about CDC in formats that would reach services and consumers. The fourth study was conducted in the early stages of CDC implementation (Orpin et al., 2016). While staff supported CDC principles, they considered that they were already working to them. Both staff and consumers were satisfied with their current arrangements, especially the emphasis on positive relationships between consumers and staff. Most saw no need for change. However, a minority of clients were dissatisfied with the limited support options available, the lack of flexibility, and the lack of transparency regarding administration fees and other charges.

Expectations of CDC

A Victorian study conducted prior to the introduction of CDC found that staff had high levels of anxiety about impending changes. Case managers were interviewed in Victoria during 2012-13 and they were highly concerned about possible changes to their work practices (You, Dunt, & Doyle, 2017). It seems that staff anxiety decreases when they gain experience with CDC and they become accustomed to the changes.

Carers

Carers play an important role is self-managed programs. Larkin and Mitchell (2015) conducted a literature review of papers examining carers in self-managed programs. They concluded that carers carry a heavy administrative burden, often with few options and insufficient support. The authors argued for further research and consultations with carers to find the best ways to support them. COTA Australia CDC trial noted these findings and has included carers in the design and evaluation of the program.

Workforce

Many studies show that the success of CDC programs is dependent upon the availability of suitable workers (Ismail et al., 2017; Mavromaras, Moskos, Mahuteau, & Isherwood, 2018). Support workers, planners, advisors and coordinators are essential to achieving successful outcomes. The complex array of issues support workers face is detailed in a *Background Paper* released by Victorian Government for their inquiry into the 'on-demand workforce' (Victoria Government, 2019). The *Background Paper* notes positive opportunities for flexibility and control, and negative consequences of feeling exploited in precarious employment. This inquiry aims to learn from the experience of support workers. The COTA Australia trial will monitor the concerns raised in the *Background Paper*.

Risks

The possibility of vulnerable older consumers being abused or exploited in self-managed programs is widely discussed in the literature (Ismail et al., 2017; Manthorpe & Samsi, 2013). UK and US studies found no significant correlations between self-managed care and personal abuse, but there were some instances of financial abuse, allegedly by the support workers (Brown et al., 2007; Ismail et al., 2017). The UK has developed guidelines designed to minimize potential fraud and abuse (Department of Health and Social Care, 2018). This guide provides a sophisticated discussion of abuse and neglect and the responsibility to protect everyone, including with those who self-neglect.

Disability

The disability sector provides aged care with useful information about self-management based on their longer experience. Although Australia maintains distinct aged and disability legislation and policies, both fields have adopted CDC programs, and service providers and support workers increasingly work across both sectors.

A recent literature review of disability papers reporting on self-directed disability evaluations in Australia, New Zealand, parts of Europe, the UK, and the US identified key factors that contributed to positive outcomes for people self-managing support packages (Lakhani, McDonald, & Zeeman, 2018). Their conclusions concur with findings discussed above. People need information and support to make informed decisions, particularly concerning budgeting, planning and hiring support workers. Some consumers found it difficult supervising support workers they employed. Barriers to implementing CDC programs sometimes resulted from the attitudes of organisations and support workers who restricted consumer's choice and control.

The need for information and support was recognised in early Australian studies (Laragy & Ottmann, 2011). Subsequently, a framework was developed for providing information in self-directed programs (Laragy, David, & Moran, 2016). This recommends that information be: i) accessible and diverse in format, mode, source and location; ii) personalised and targeted; iii) accurate, consistent and timely; iv) from a trusted source; v) independent; vi) culturally appropriate; vii) actively promoted to 'hard to reach' groups; and viii) gender appropriate. The COTA Australia trial will review whether these factors are relevant in their program.

Conclusions

All CDC evaluations have methodological limitations that restrict the conclusions that can be drawn. Even the US *Cash & Counseling* evaluation with randomised trial and control groups had restrictions. However, looking at the findings overall, all except one study found that self-managed programs resulted in better outcomes for older people when certain conditions applied. The exception was the UK study (Woolham et al., 2017) that found no statistically significant differences in outcomes for consumers in the trial and the control groups. The COTA Australia evaluation will provide valuable evidence to further this debate.

This literature review is important to the COTA Australia self-managed trial because it identifies factors found to contribute to positive outcomes. These are surprisingly consistent across the studies. The Scottish *Guide to making Self-Directed Support Work for Everyone* (Smith et al., 2018) presents principles for self-managed programs and provides a guide that reflects most findings. The principles include: i) think differently and be creative; ii) seek solutions that may be simple but make a real difference to people's quality of life; and iii) the use of money must be clearly related to the person's plan and outcomes. Also helpful is the US handbook titled *Developing and Implementing Self-Direction Programs and Policies: A Handbook (Department of Health and Human Services, 2010)*.

Key elements identified in the literature that will contribute to positive outcomes in self-managed programs are:

- Time to implement cultural and procedural changes
- Information provided in accessible formats
- Outreach to vulnerable and marginalised communities
- Carers consulted and supported
- Support and advice provided when needed
- Sufficient funds allocated to meet social as well as personal care needs
- Services available for consumers to purchase
- Support workers available to be employed
- Risks monitored and addressed

The COTA Australia CDC trial will be guided by this literature review that identified success factors in self-managed programs.

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