



*cutting through complexity*

# Evaluation of the consumer-directed care initiative – Final Report

Department of Health and Ageing

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KPMG have indicated within this report the sources of the information provided. We have not sought to independently verify those sources unless otherwise noted within the report.

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## Executive summary

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### *The consumer-directed care initiative*

The consumer-directed care initiative ('the initiative') aims to provide community aged care consumers with greater control of their lives by allowing them, to the extent that they are capable and wish to do so and relative to their assessed care need level, to make informed choices about the types of care services they access, and the delivery of those services, including who will deliver the services and when they are delivered.

As part of the initiative, a total of 1000 non-ongoing flexible care places were allocated through the Innovative Pool Program for consumer-directed care (CDC) packaged care: 500 places in 2010-11 and a further 500 in 2011-12. Four-hundred CDRC packages were also provided to carers and funded through the National Respite for Carers Program (NRCP): 200 packages in 2010-11 and a further 200 in 2011-12. At the time of the evaluation CDC and CDRC packages were expected to be available until 30<sup>th</sup> June 2012.

### *The evaluation*

The purpose of this evaluation was to assess the effectiveness of consumer-directed care approaches in the Australian community aged care context by examining the implementation, operation, impact and cost of the consumer-directed care initiative.

There were four key objectives for the evaluation:

1. to evaluate the Department's implementation of the initiative and ongoing administration, and the operationalisation of CDC by providers and centres (process evaluation)
2. to evaluate the impacts or benefits of the CDC initiative on participants and their carers, including impacts or benefits in terms of their ability to achieve their personal goals and on their quality of life, recognising the length of time that the CDC initiative has been in operation (outcomes evaluation)
3. to determine the cost of the initiative and assess the value for money of consumer-directed care in community aged care, relative to the outcomes achieved (cost analysis)
4. to identify barriers to success and key achievements, and key lessons from the initiative to inform future roll-out.

The scope of the evaluation encompassed the first 500 CDC packages and 200 CDRC packages approved in 2010-11. It did not encompass the further 500 CDC and 200 CDRC packages approved in 2011-12.

### *Implementation and operation of the initiative – program implementation*

The implementation of the program was done over a relatively short period of time, and the length of time between providers being informed that they had secured CDC or CDRC packages and rolling-out packages to participants was very short. As a result providers had little time to develop their approach to CDC and CDRC and to select participants.

Providers indicated that they would have preferred more *proactive* support from the Department during the implementation, in addition to the helpdesk and frequently asked questions that the Department published. Providers suggested that some initial training or face-to-face briefings by the Department would have been useful, as well as more regular information exchange and discussion

with other providers and the Department. In addition, providers would have preferred earlier provision of operating manuals.

The degree to which providers were already flexible and person-centred in their approach influenced the degree of change that was needed for them to implement CDC. This was evident from the variations and inconsistencies in the way CDC was implemented and operated across different providers, and the degree to which CDC was different from standard packaged care. Variations were particularly notable in planning processes, in providers' degree of flexibility around the range and choice of services offered to participants, and in providers' openness to allowing package funds to be used for innovative or non-traditional supports.

#### *Implementation and operation – participant selection and planning*

In selecting potential participants, providers commonly targeted those with a carer or a family member actively involved in the older person's life (for consumer-directed high care (CDCH) participants and consumer-directed high care – dementia (CDCHD) participants). For low care participants, providers looked to people who they thought had sufficient capacity and who might have an interest in self-direction. There was a higher level of interest by potential participants in CDCH and CDCHD packages than there was in consumer-directed low care (CDCL) packages.

CDRC providers tended to target potential participants who were already known to them, and who were considered a 'priority' (such as carers under stress or who had little or no access to formal supports), and who had the 'capacity' to participate in CDRC. A number of providers targeted younger carers of frail older people who they considered were more appropriate for CDRC than older carers.

CDC and CDRC and planning processes were either goal-based or menu-based. Goal-based planning focussed on identifying the goals, desires and objectives of the participant and carer, and then looking to identify possible care and support options. Menu-based planning focussed on the Aged Care Assessment Team (ACAT) needs assessment and provision of a list of available supports, providers and price list to the participant or carer. Goal-based planning tended to be used with CDRC participants, for CDCH and CDCHD participants, and by providers who were more 'person-centred' in their approach to CDC and CDRC.

#### *Implementation and operation – delivery and coordination*

CDC and CDRC were characterised by an initial period of intensive assessment and planning involving participants, followed by an ongoing and variable level of support coordination and management once services were in place.

There were different models for delivery and coordination of CDC and CDRC. The predominant model offered participants 'enhanced choice' of supports, with providers maintaining responsibility for coordinating and managing packages. Other models incorporated different levels of participant control and self-management, with the level of support coordination and management undertaken by providers decreasing as participants' moved towards managing their package themselves.

Most participants were able to manage their package to some degree, at least to the level of making simple, day-to-day bookings and scheduling changes, maintaining timesheets, and managing problems such as support workers being late. However, few participants took on a substantial self-management role – either because they were not given that option by their provider, had no interest in self-managing their package and their support arrangements, or did not feel that they were able to.

#### *Extent to which CDC was person-centred and increased choice and control*

CDCH and CDCHD participants and their carers were more interested and actively involved in planning and decision-making. CDCL participants were less interested in the planning aspects of CDC, particularly if they had transferred from a CACP and were satisfied with their current support arrangements. The majority of new participants were focussed on which supports they could access – similar to new standard package recipients.

CDCH and CDCHD participants, and specifically their carers, appeared to be more actively involved in planning and decision-making. Some participants and carers (usually younger carers) with prior experience of community care had clear ideas about what they wanted in terms of supports, and what they wanted to be 'different' with their CDC package – largely driven by dissatisfaction with their previous package.

Participants chose similar types of supports as those available under standard packaged care and generally used their package for 'core services'. They exercised choice and control over how the services were delivered, including choice of support worker, and being flexible in delivery days/times and tasks undertaken by support workers. Some participants also used part of their package funds for innovative and non-traditional supports, though provider attitudes to requests for supports that were different from the 'usual menu' of services varied.

Several CDC providers had concerns about balancing the consumer choice element of CDC with the provider's duty of care. Several providers gave examples of requests by participants or carers for specific items or supports that they had refused – mainly because they considered that the request would compromise the participant's care and wellbeing (for example, where it reduced the level of personal care or clinical care that a participant could access). Other providers were also concerned by participants choosing to build up a sizeable contingency fund by foregoing some regular supports. While providers discussed and negotiated alternatives with participants, it highlighted one of the key tensions in the CDC model.

#### *Extent to which CDC enhanced community-based care*

Even after a short period of operation, CDC appeared to have a positive impact on participants' level of satisfaction with various aspects of their life. Participants reported increased satisfaction with their ability to participate in social and community activities, their ability to visit family and friends, the quality of their home life and close relationships, and their health and wellbeing.

Satisfaction was generally higher for CDCH participants than for CDCL, indicating that there is potentially more benefit for people with higher levels of need (and receiving more sizeable packages). Satisfaction was also generally higher for CDC participants who had prior experience of packaged care compared with those participants with no prior experience of packaged care, indicating that CDC represents an improvement over standard packaged care for many participants.

On the validated measure of wellbeing, however, there was no statistically significant difference between the CDC participant group and the standard packaged care comparison group.

#### *Extent to which CDRC was person-centred and increased choice and control*

There were considerable benefits for carers from being able to plan supports in advance, and from simply being involved in the planning process. For many carers, they felt that they were being recognised and valued as carers – often for the first time.

CDRC allowed carers to focus on themselves, rather than the person they care for. Most participants were actively involved in planning, though for some it took a while to determine what they wanted to use their package for.



The relationship with the coordinator was particularly important and valued by participants. The strength of this relationship (and the effectiveness of the coordinator's skills) seemed important for clients in building their capacity to self-identify needs and goals, building their capacity to self-manage, and receiving emotional support and advice on a wide range of issues related to their caring.

CDRC provided more choice of supports and more control and influence over the supports carers received than the National Respite for Carers Program (NRCP) or other community care programs that carers had experienced.

#### *Extent to which CDRC enhanced community-based care*

Even after a short period of operation, CDRC had a considerable positive impact on carers. Many participants felt that their capacity to continue in their caring had increased since commencing on the package, and for many having a package gave them the chance to put energy back into their caring role.

CDRC also had a positive impact in terms of carers' level of satisfaction with different aspects of their life - including their ability to participate in social and community activities, their ability to visit family and friends, the quality of their home life and close relationships, and their health and wellbeing.

However, the relatively generous size of a CDRC package during the period of the evaluation is likely to have had some impact on the benefits realised.

It is also noted that, on the single measure of wellbeing, there was no statistically significant difference between the CDRC participant group and carers accessing supports through NRCP.

#### *Cost and cost-effectiveness of the initiative*

Providers incurred costs relating to the development and set-up of CDC and CDRC, and met these costs themselves. While some set-up costs will not be incurred again by existing providers if the initiative is expanded, new providers can expect to incur some costs. Further, there is likely to be additional costs incurred for systems development as the number of packages reaches a critical mass and processes need to be automated.

Providers also incurred some ongoing costs which were not being met from package funds. The extent to which these costs will continue is unclear, though they may decline over time as providers become more familiar with the approach and participants take on a greater self-management role.

Given the timing of the evaluation it was not possible to undertake a cost-effectiveness analysis. It is therefore not possible at this point in time to say whether consumer-directed care is cost-effective, or more or less cost-effective than standard packaged care and respite. A cost effectiveness analysis is only feasible once the initiative has been operating for a longer period, that is, when outcomes from the initiative are clearer and are able to be quantified more precisely, and when costs of the initiative have had time to stabilise.

## Glossary

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<b>ACAT</b>	Aged Care Assessment Team (known was Aged Care Assessment Service, or ACAS, in Victoria)
<b>Administration</b>	For the purposes of this report, administration of the individual CDC or CDRC budget, including some liaison with service providers, reconciliation of accounts, payment of invoices, and provision of monthly budget statements to participants
<b>Agency</b>	See <i>support provider</i>
<b>Brokered services</b>	Care or services provided to a participant by a community aged care provider other than the participant's CDC provider or CDRC provider
<b>Budget</b>	The amount of funding allocated to a CDC or CDRC participant. Budgets are generally expressed as an annual and/or monthly amount
<b>Carer</b>	A person who provides informal care to a care recipient
<b>Care planning and management</b>	<p>Initial and ongoing assessment, planning and management of supports for CDC participants by appropriately qualified and trained staff, with the involvement of the care recipient and their carer (where appropriate). It includes budget planning; provision of information, advice and support to participants; provision of assistance with establishing supports (including initial liaison with support providers); coordination of supports and changing support arrangements when required; review of care plans; and monitoring of care and supports for quality and safety purposes.</p> <p>For the purposes of this report, the term is used in reference to CDC packages.</p>
<b>Care plan</b>	Document outlining the care and services to be delivered under a CDC or CDRC package
<b>Care recipient</b>	The person who is being cared for (by a carer) or who is receiving formal services
<b>Case management</b>	For the purposes of this report, refers to case management for people with dementia who experience behaviours of concern and is an essential component of care planning and delivery of CDCH and EACHD packages. It includes preparation of a detailed care plan including behaviour management plan; involvement of a range of service partners through case conferencing, care planning, service delivery, monitoring and review; maintenance of relationships with specialists; and monitoring of approaches and strategies in response to the changing needs of care recipients and carers.
<b>Case management and coordination</b>	Initial and ongoing assessment, planning and management of supports for participants by appropriately qualified and trained staff, with the involvement of the care recipient and their carer (where appropriate). It includes budget planning; provision of information, advice and support to participants; provision of assistance with establishing supports (including initial liaison with support providers); coordination of supports and

changing support arrangements when required; review of care plans; and monitoring of care and supports for quality and safety purposes.

For the purposes of this report, the term is used in reference to CDRC packages.

<b>CACP</b>	Community Aged Care Package (a low-level standard care package)
<b>CDC initiative</b>	Refers collectively to the program comprising packaged consumer-directed care (including CDCL, CDCH and CDCHD packages) and consumer-directed respite care
<b>CALD</b>	Culturally or linguistically diverse
<b>CDC provider</b>	Community aged care provider which holds the CDC package funds and is responsible for care planning and budget management for CDC participants under the CDC model
<b>CDRC provider</b>	A CRCC, which holds the CDRC funds and is responsible for care planning and budget management for CDRC participants
<b>CDCH</b>	Consumer-directed care, high care (a high-level consumer-directed care package)
<b>CDCHD</b>	Consumer-directed care, high care - dementia (a high-level consumer-directed care package for people living with dementia)
<b>CDCL</b>	Consumer-directed care, low care (a low level consumer-directed care package)
<b>CDRC</b>	Consumer-directed respite care
<b>CRCC</b>	Commonwealth Respite and Carelink Centre (standard respite and CDRC providers)
<b>Consumer</b>	For the purpose of this report, a collective reference to a direct or indirect user of community aged care or respite services. Includes a participant, carer or care recipient
<b>the Department</b>	Department of Health and Ageing – funder of standard care packages, NRCP and other respite services, CDC and CDRC
<b>EACH</b>	Extended Aged Care at Home (a standard care package)
<b>EACHD</b>	Extended Aged Care at Home – Dementia (a standard care package for people living with dementia)
<b>Formal services</b>	Services provided by an aged care or other provider, for which they are paid or funded
<b>HACC</b>	Home and Community Care
<b>In-house services</b>	Care or service provided to a CDC or CDRC participant by the same community aged care provider or CRCC which is also the CDC or CDRC provider for that participant
<b>Informal services</b>	Services provided by carers, family members, friends, and other community members, for which they are not paid or funded
<b>NESB</b>	Non-English speaking background



<b><i>NRCP</i></b>	National Respite for Carers Program
<b><i>Participant</i></b>	The person to whom the CDC or CDRC package is allocated and who receives the bulk of care and services under the package
<b><i>Standard packaged care</i></b>	CACP, EACH or EACHD
<b><i>Standard respite services</i></b>	Respite services coordinated through CRCCs and funded under the NRCP and other Commonwealth Government programs.
<b><i>Support provider</i></b>	Community aged care or other provider engaged to deliver care or supports funded through a CDC or CDRC package
<b><i>Support worker</i></b>	Paid workers who deliver formal care and support to older people, including CDC and CDRC participants.
<b><i>Younger carer</i></b>	Carer of a frail older person, aged under 65 years (or under 50 years for Aboriginal and Torres Strait Islanders)

# 1 Introduction

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## 1.1 Introduction

The Department of Health and Ageing is undertaking an initiative to demonstrate consumer-directed care models of community aged care service delivery under the Innovative Pool Program and the National Respite for Carers Program.

CDC aims to provide community aged care consumers (care recipients and carers) with greater control of their lives by allowing them, to the extent that they are capable and wish to do so and relative to their assessed care need level, to make informed choices about the types of care services they access and the delivery of those services, including who will deliver the services and when they are delivered.

As part of the initiative, a total of 1000 non-ongoing flexible care places were allocated through the Innovative Pool Program for CDC packaged care: 500 places in 2010-11 and a further 500 in 2011-12. Four-hundred CDRC packages were also provided for carers and funded through NRCP: 200 packages in 2010-11 and a further 200 in 2011-12. At the time of the evaluation CDC and CDRC packages were expected to be available until 30<sup>th</sup> June 2012.

KPMG were engaged in October 2010 to undertake an evaluation of the consumer-directed care initiative, and the evaluation was conducted from November 2010 to November 2011. The findings from the evaluation will inform future policy and program management decisions related to consumer-directed care in community aged care.

## 1.2 Purpose and structure of this report

This report presents the main findings of the evaluation, highlights lessons learnt from the initiative to date, and proposes strategies and actions for consideration should CDC be expanded in future years.

The remainder of this report is structured as follows:

- |                  |   |
|------------------|---|
| <i>Chapter 2</i> | Presents a description of the consumer-directed care initiative and the environment within which it operates  |
| <i>Chapter 3</i> | Provides an overview of the evaluation, including evaluation approach and key evaluation questions  |
| <i>Chapter 4</i> | Presents a profile of CDC and CDRC participants and the supports they accessed  |
| <i>Chapter 5</i> | Discusses the implementation and operation of the initiative, including program implementation, initiation and planning and delivery and coordination of CDC and CDRC |
| <i>Chapter 6</i> | Discusses the impact of the initiative for CDC participants and their carers,   |

including the extent to which CDC was person-centred and increased consumer choice and control, and the extent to which CDC enhanced community-based care, quality of life and wellbeing for participants and their carers

- Chapter 7* Discusses the impact of the initiative for CDRC participants and the people they care for, including the extent to which CDRC was person-centred and increased consumer choice and control, and the extent to which CDRC enhanced community-based care, quality of life and wellbeing for participants and the people they care for
- Chapter 8* Discusses the impact to date on providers and the community care service system more broadly
- Chapter 9* Discusses the cost of the initiative, value for money and financial sustainability of the initiative
- Chapter 10* Summarises the key findings of the evaluation
- Chapter 11* Summarises lessons learnt from the initiative, and strategies for consideration to inform any future roll-out of the initiative

### 1.3 Terminology

The ‘*CDC initiative*’ (or ‘*the initiative*’) are overarching terms used throughout this report, and encompass both consumer-directed care (CDC) package component and consumer-directed respite care (CDRC) package component of the initiative.

Throughout this report, there are references to care recipient and carers, and to ‘CDC participants’ and ‘CDRC participants’. ‘*CDC participants*’ are care recipients in receipt of a CDC package. ‘CDC participants’ do not include the carers of people receiving the CDC package. ‘*CDRC participants*’ are carers in receipt of a CDR package. ‘CDRC participants’ do not include the people who were being cared for by the CDRC participant.

A *care recipient* is a person who receives formal community care services and/or care from an informal carer (such as their spouse or other family member). A *carer* refers to the person who provides informal care to a person in need of support.

Acronyms used throughout the report were listed in the glossary at the beginning of this report.

## 2 The consumer-directed care initiative

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### 2.1 Introduction

This chapter outlines the background and context for the consumer-directed care initiative, including the aged care environment in which the initiative operate, a description of the initiative, and an overview of consumer-directed approaches in other jurisdictions and settings.

### 2.2 Community aged care and respite environment

The Australian Government funds community aged care and respite services to assist frail older people, and the carers of frail older people, to remain living at home:

- Community Aged Care Packages (CACPs) are individual packages of care and services for frail older people requiring support wishing to remain living in their own home. CACPs provide an alternative to low level residential aged care.
- Extended Aged Care at Home (EACH) packages provide a higher level of support and assistance that is an alternative to high level residential aged care.
- Extended Aged Care at Home, Dementia (EACHD) packages target people living with dementia who experience behaviours of concern and psychological symptoms associated with dementia which impact on their ability to live independently. This is an alternative to high level, dementia-specific residential care.

Each of these packaged care programs are governed by the *Aged Care Act 1997* and the Aged Care Principles. Need and eligibility for community aged care is assessed by Aged Care Assessment Teams (ACATs), as it is for residential aged care. Packages are delivered by approved providers of aged care services. The Government allocates numbers of packages to providers (based on a population planning benchmark) and pays a subsidy for each package to the provider. The level of subsidy relates to the care level (i.e. CACP, EACH, EACHD).

The National Respite for Carers Program (NRCP) commenced in 2004. It provides funding for Commonwealth Carelink and Respite Centres, which provide information and support to carers as well as referral to respite services. The program also funds direct and indirect respite services for carers (direct services include in-home, centre-based and residential respite services; indirect services include other services not directly related to caring, but which give carers assistance with or relief from their caring role). NRCP services particularly target carers of people living with dementia (including those with challenging behaviour), carers of frail older people, carers of younger people with moderate to profound disability, and people with terminal illness.

There are several identified special needs groups for community aged care and NRCP services identified in the *Aged Care Act*: people from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander peoples, financially and socially disadvantaged people, and people living in rural and remote areas. Additional special needs groups for community aged care are people at risk of or experiencing homelessness, veterans, and people who lived in care during their formative years (care-leavers or 'Forgotten Australians').

## 2.3 Description of the CDC initiative

In July 2010, the Australian Government commenced the CDC initiative, comprising consumer-directed care (CDC) and consumer-directed respite care (CDRC).

The CDC initiative responds to trends towards self-direction in community care and other service settings in Australia and internationally, and anticipates demand for more choice and control by the 'baby boomer' generation.

### *Aims of the initiative*

The aim of the CDC initiative is to provide community aged care consumers (care recipients and carers) with **greater control of their lives** by allowing them, to the extent that they are capable and wish to do so and relative to their assessed care need level, to **make informed choices** about the types of care services they access, and the delivery of those services, including who will deliver the services and when they are delivered.

### *Principles*

The CDC initiative is governed by eight principles:

1. *Integrated:* CDC should be integrated into existing programs as an optional mode of care delivery and operate within the constraints of the current legislative arrangements.
2. *Responsive:* CDC should be responsive to changing needs and circumstances of care recipients and carers, and enable adjustment of budgets and services to meet those needs.
3. *Inclusive:* CDC should take into account the needs of care recipients and their carers and consider its contribution to or impact on the social inclusion of care recipients.
4. *Equitable:* Care recipients with the same or similar needs and circumstances should receive comparable allocations of budgets and services.
5. *Optional:* CDC should be offered to care recipients as a voluntary option.
6. *Care recipient and carer-centred:* CDC should take into account the needs and views of care recipients and carers and support them having control and choice over their care.
7. *Supportive:* Care recipients and carers should be provided with a range of support to make informed decisions and practise CDC, including education and advocacy.
8. *Sustainable:* CDC should provide an affordable, long term option for delivery of care for government that meets the needs of care recipients and carers.

### *CDC and CDRC packages*

#### *Consumer-directed care (CDC) packages*

500 non-ongoing flexible care places were allocated to approved aged care providers through the Innovative Pool Program for CDC packaged care in 2010-11 and 2011-12. An additional 500 CDC packages were approved from July 2011, though these packages were not within the scope of this evaluation.

The target group for CDC packages are frail older people aged 70 years and over (or 50 years and over for Aboriginal and Torres Strait Islander people), with complex care needs who wish to remain living in their own home.

There are three levels of subsidy for CDC packages, broadly aligned to Australian Government funded aged care packages:

- CDC Low Care (CDCL) – similar to CACPs and may include services such as personal care, social support, transport, home help, meal preparation and gardening. The Commonwealth subsidy level in 2010-11 was \$13,158 per package.
- CDC High Care (CDCH) – similar to EACH packages and may include services such as nursing, domestic assistance, in-home respite, personal care, transport and social support. The subsidy level in 2010-11 was \$43,982 per package.
- CDC High Care Dementia (CDCHD) – similar to EACHD packages providing services to people living in the community with high level, complex care needs who experience behaviours of concern and psychological symptoms associated with dementia. These needs have a significant impact upon their ability to live independently. The subsidy level in 2010-11 was \$48,504 per package.

The subsidy paid to providers is based on the participant's ACAT-assessed care need level (as it is for standard packaged care). Individual budgets or allocations for each CDC participant are determined by the CDC provider, and do not need to correspond directly to the subsidy levels. CDC participant allocations are administered by CDC packaged care providers. Providers may charge an administration fee for managing the individual budget.

#### *Consumer-directed respite care (CDRC) packages*

In addition to CDC packages, 200 consumer-directed respite care (CDRC) packages were provided in 2010-11 and 2011-12 to carers registered with the NRCP, and were funded through the NRCP. An additional 200 CDRC packages were approved from July 2011, though these packages were not within the scope of this evaluation.

Target recipients for CDRC packages are carers of frail older people aged 65 years and over (or aged 50 and over for Aboriginal and Torres Strait Islander people), and carers of people living with dementia and/or challenging behaviour.<sup>1</sup>

CDRC package funds are administered by 16 CRCCs. The CDRC package budget was \$4,200 per package in 2010-11. An additional \$2,000 per package was allocated to cover expenses relating to the administration of each package, client management, and participation in the evaluation.

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<sup>1</sup> In addition, the following carers are able to utilise a CDRC package where carers of frail older people have not been identified:

- carers of younger people (aged under 65 years or under 50 years for Aboriginal and Torres Strait Islanders) with moderate, severe or disabilities who are living at home
- carers of people with a terminal illness in need of palliative care.



### *Provider and participant roles and responsibilities*

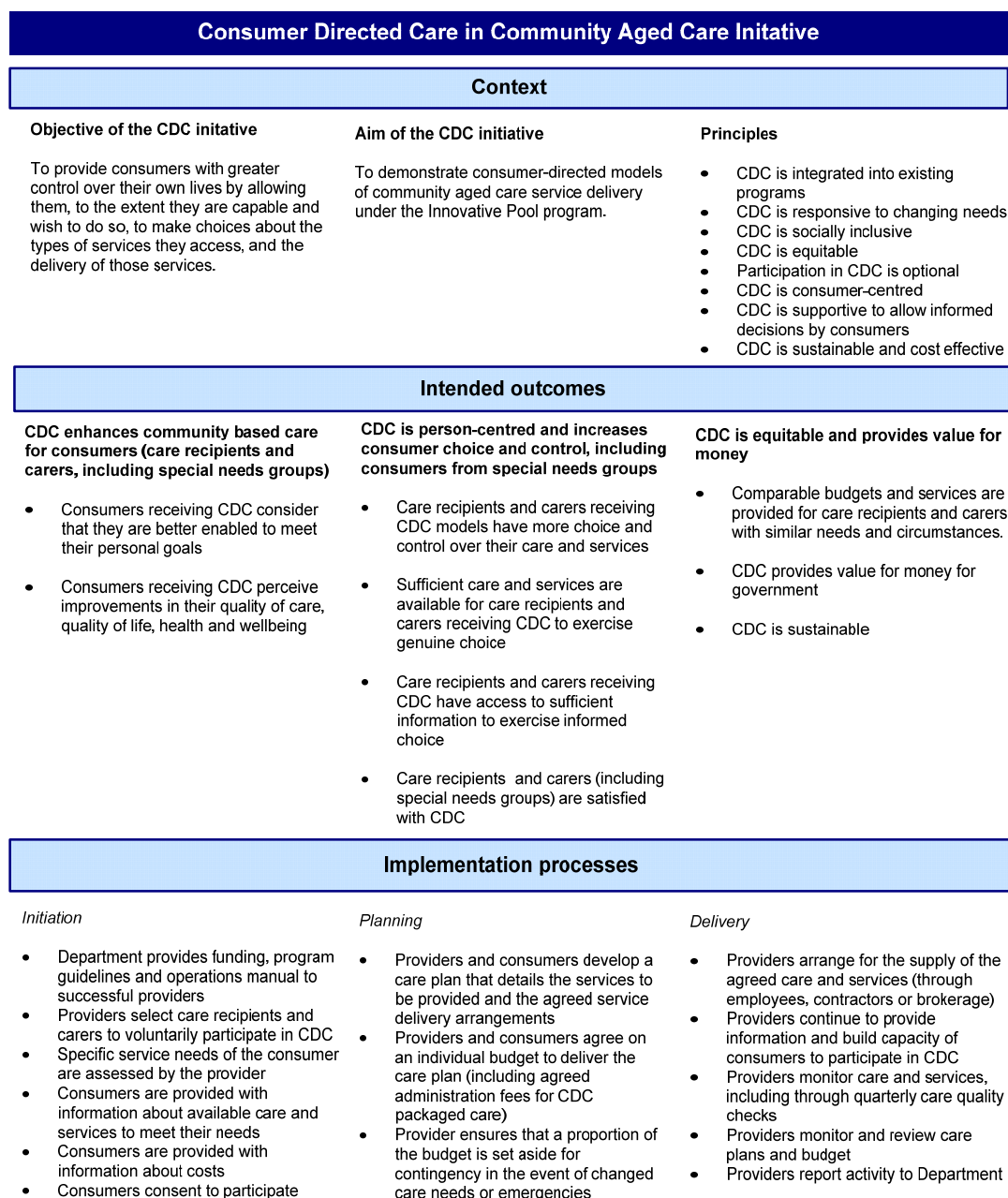
CDC and CDRC providers are responsible for selecting participants, undertaking needs assessments and care planning, administering participant allocations and organising and coordinating the delivery of supports.

Participants are actively involved in all aspects of planning and decision-making, and are able to take on aspects of package administration, management, and support coordination themselves – to the extent that they are able to and within the bounds permitted by their packaged care provider and the *Aged Care Act*.

### *Program logic*

Figure 1 provides a diagrammatic map highlighting the context and principles for the CDC initiative, the intended outcomes of the initiative, and the implementation processes required to achieve those outcomes.

Figure 1: Program logic for the CDC initiative



NOTE: All references to 'CDC' include consumer directed packaged care and consumer directed respite care, unless otherwise specified.

Special needs groups include people from Aboriginal and Torres Strait Islander people, people from non-English speaking backgrounds (culturally and linguistically diverse backgrounds), people who live in rural and remote areas, people who are financially or socially disadvantaged, veteran's, homeless people, Care-leavers. Key issues may also include communities with groups of people who will significantly benefit from CDC places, eg people with dementia, people with challenging behaviour and people with limited access to existing services.

Source: KPMG

## 2.4 Consumer-directed approaches in other jurisdictions and settings – a review of literature

### *Definition and development of CDC approaches*

Consumer-directed care is both a philosophy and an orientation to a service delivery format where consumers, including care recipients and their carers, can choose and control the services they get, to the extent that they are capable and wish to do so (AACS 2010, Rees 2010). Typically the main objective of CDC is to offer consumers more choice and control than they would have from agency directed programs (Tilly and Rees 2007, Howe 2003).

The development of consumer-directed (or self-directed) approaches is commonly associated with the disability rights and self-determination movements in North America and the UK in the 1970s, which resulted in the establishment of independent living grant programs in the 1980s. Today, CDC models are widely used in the Australian disability support sector, and all states and territories now offer some form of consumer or self directed approach to planning, funding and involving person-centred planning, individual budgets for adults requiring community-based care, and are actively working to expand those schemes (Productivity Commission 2011).

In most international and Australian jurisdictions, CDC is an *optional alternative* to agency-directed care. Many older people appear to prefer agency-directed services (Tilley 2000). However, it should be noted that the Australian CDC initiative is the first CDC model internationally that has been specifically designed for older people (others were designed for younger people with disabilities, and expanded to include older people).

### *Features of consumer-directed care models*

CDC programs typically include person-centred approaches to needs assessment and planning resulting in an individual care plan, and would usually have some form of individual budget option (possibly including an indicative upfront allocation to purchase services agreed under the plan). CDC programs will always feature some degree of consumer choice and control over the types of supports they can access and the providers that deliver those services.

Common features of consumer-directed care models are discussed below.

#### *Consumers are actively involved in the planning of their supports*

Consumer-directed care necessarily involves more active involvement of the consumer in the planning and design of the supports they receive, and the development of a person-centred or individual plan which considers their needs and goals as an individual, as well as their family/carer and life circumstances. This person-centred approach to planning is a key feature of successful consumer-directed models.

#### *Consumers are provided with personal budgets or individual funding allocations*

Along with personalised planning, one of the key features of a consumer-directed care approach is individualised funding allocations or personal budgets over which consumers have some form of control. The degree to which consumers have control over their allocation or budget, and the limitations placed on how funds can be used, varies significantly across models.

Most models have an option of direct payment to consumers in the form of cash or vouchers, or co-managed budgets where the consumer and a third party jointly manage a personal budget. Where funds are co-managed, a third party holds the funds but the consumer has significant control over expenditure. In some jurisdictions (such as the UK), personal budgets can be made up of both direct payments and co-managed funds.

### *Consumers have choices over the supports they receive and the design of these supports*

Consumer choice can relate to two things: choice of services and choice of provider of services, and typically consumer-directed care models allow both. However, consumer-directed care models differ in the degree of choice that consumers have, and in particular the limits placed on consumer choice:

- At one end of the continuum of choice, consumers can receive direct payments and be relatively unrestricted in terms of the supports that they can purchase and the providers of these supports. In a number of European models consumers can receive cash payments to directly employ support workers, and in some cases employ family members, rather than use their allocation for specific service types from pre-approved providers.
- At the other end, consumers can only choose from a limited menu of services (which may be based on pre-defined 'service types') from pre-approved or accredited providers. This is evident in early consumer-directed models applied to specific disability service programs in Australia (for example, the Community Participation and Transition to Work programs for people with a disability leaving school in NSW).

The literature shows that, regardless of the extent of choice permitted within the model, a critical enabler for any effective consumer-directed care program is support for informed decision-making by consumers and carers (Chenoweth 2009).

### *Outcomes of CDC*

The literature suggests many broad benefits for consumers and carers participating in CDC models: increased hours of paid care, increased consumer and carer satisfaction, improved health and wellbeing outcomes, reduced unmet needs, and potential for cost savings in comparison to agency-directed approaches.

Studies of CDC models in Europe and North America consistently suggest overall positive impacts of CDC on the level of consumer satisfaction with the care they receive, level of consumer independence, wellbeing and quality of life, and perceived quality of care (Glendinning 2008, Wiener 2007, Tilly and Bectal 1999, Benjamin et al 1998), increased hours of paid care (Glendinning 2008, Foster 2005), fewer unmet needs and adverse health events, reduced nursing home admissions (Carlson 2007), and less reliance on case management (Laragy and Naughtin 2009). Consumers who participate in CDC are generally at least as satisfied or more satisfied with their care outcomes (Ottmann, Allen and Feldman 2009).

However, almost without exception<sup>2</sup>, the positive impacts were lower for older people than for younger people. In some cases, older people experienced worse outcomes and greater anxiety

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<sup>2</sup> In one US study of a direct payment style CDC model, older people were more satisfied than younger CDC participants (Wiener, Anderson and Khatutsky 2007), but the bulk of the literature – and in particular

related to managing an individual budget (Glendinning 2008). Australian consumer research has shown that many older people see CDC as burdensome rather than empowering (Carers Victoria 2010).

Although there is little literature on the impact of CDC on carers (as opposed to care recipients), there is some suggestion of positive impacts. CDC approaches can provide more opportunities for carer involvement in planning and delivery of services, and greater consideration of the carer's own needs (Arksey 2009). The UK randomised control trial found that carers' satisfaction with and level of involvement in the initial assessment and care planning process was a predictor of their overall satisfaction with CDC (ibid).

CDC is cited as a potentially more cost effective, financially sustainable model of care which can better respond to the pressures of an ageing population by supporting ageing in place and reducing inpatient and residential care, as well as meeting increasing consumer demand for more flexibility and control (Laragy and Naughtin 2009, Lundsgaard 2005).

European and American studies of CDC models have found CDC models to be more cost effective than agency-directed models where the CDC model is based on a direct payment system. This is because of the reduced labour costs associated with direct employment of support workers, particularly relatives, and reduced agency case management costs.

It is not clear whether individual budget models of CDC that involve shared or co-managed budgets – either alongside direct payments (such as the Victorian and UK models) or instead of direct payments (such as the Australian CDC model) are any more or less cost effective than traditional agency-directed models (Arntz 2008).

Further detail on consumer-directed approaches in other jurisdictions is contained in Appendix A.

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the findings from randomised control group evaluations of CDC models – find the opposite: that older people are less satisfied.

## 3 Evaluation of the consumer-directed care initiative

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### 3.1 Introduction

This chapter provides an overview of the evaluation, including the purpose and objectives of the evaluation, key evaluation questions, and broad approach to the evaluation. The chapter also identifies some of the challenges and limitations with the evaluation.

### 3.2 Evaluation purpose and objectives

The primary purpose of this evaluation was to assess the effectiveness of consumer-directed care approaches in the Australian community aged care context by examining the implementation, operation, impact and cost of the consumer-directed care initiative.

There were four key objectives for the evaluation:

1. To evaluate the Department's implementation of the initiative and ongoing administration, and the operationalisation of CDC by providers and centres (*process evaluation*)
2. To evaluate the impacts or benefits of the CDC initiative on participants and their carers, including impacts or benefits in terms of their ability to achieve their personal goals and on their quality of life, recognising the length of time that the CDC initiative has been in operation (*outcomes evaluation*)
3. To determine the cost of the initiative and assess the value for money of consumer-directed care in community aged care, relative to the outcomes achieved (*cost analysis*)
4. To identify barriers to success and key achievements, and key lessons from the initiative to inform future roll-out.

### 3.3 Evaluation scope and timing

The evaluation considered the implementation, operation, impact and cost of both CDC packages and CDRC packages, which together comprise the consumer-directed care initiative.

Importantly, the scope of the evaluation was limited to the first round of 500 CDC packages and 200 CDRC packages, which were approved and allocated to providers in late 2010. The evaluation did not consider the subsequent second round of CDC and CDRC packages approved in early 2011 for allocation from July 2011.

The evaluation commenced in November 2010, with the majority of the evaluation data collection activities occurring during the period June to September 2011.

### 3.4 Evaluation questions

The evaluation was guided by a core set of questions which the evaluation sought to address – three outcomes evaluation questions and three process evaluation questions.

The *outcomes evaluation* questions were organised around the three core outcomes identified in the program logic:

1. To what extent does CDC enhance community-based care for care recipients and carers?
2. To what extent is CDC person-centred, and how does it increase consumer choice and control?
3. Is CDC equitable and providing value for money?

The *process evaluation* questions were organised around the three core implementation and operational processes identified in the program logic:

1. How effective were the CDC initiation processes?
2. How effective were the CDC planning processes?
3. How effective is the delivery of CDC?

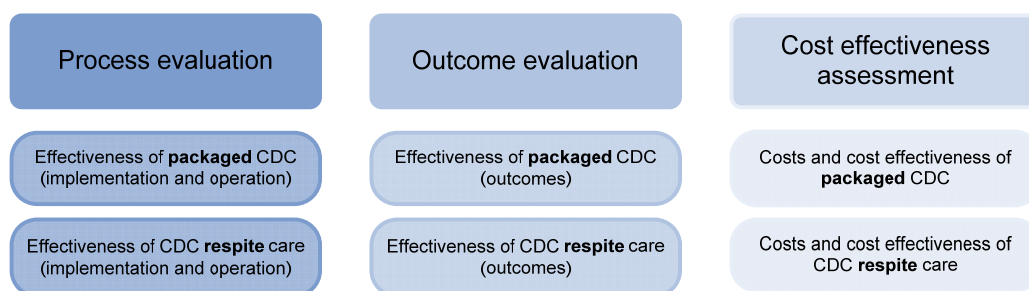
For each of these questions, a number of aspects and sub-questions were identified, together with data sources and collection methods for each of these aspects and sub-questions. These were outlined in the *Evaluation Framework*, and have been replicated in the *Methodology Report* which accompanies this report.

### 3.5 Methodological approach

The methodological approach underpinning the evaluation recognised the need to undertake the evaluation at two levels (outcomes and process), and to evaluate the two CDC components (packaged care and respite care) separately.

Figure 2 below summarises the links between the different levels and elements of the evaluation.

Figure 2: Components and key elements of the CDC evaluation



An *Evaluation Framework* was developed to guide each stage of the evaluation. The framework included a number of evaluation tools (consumer and carer surveys and service provider data collection templates) to collect the data for the evaluation. Ethics Committee approval was granted for the data collection tools.

A mixed method approach to data collection was used, using a mix of quantitative and qualitative methods appropriate to the target groups. The range of data collection methods used in the evaluation is described below:

### *Participant and comparison group surveys*

Paper-based surveys were sent to all CDC and CDRC participants as well as an equal number of people in packaged care and respite comparison groups in June 2011. The surveys sought participants' perspectives of the impact and benefits of CDC/CDRC compared with standard packaged care, as well as their experiences relating to the planning, budgeting and service delivery aspects of CDC/CDRC.

In addition, the surveys included the five-item ICECAP-O tool to derive a single measure of wellbeing for each of the CDC and CDRC participant and comparison groups.<sup>3</sup> The ICECAP-O provides a broader measure of wellbeing and 'quality of life' than other validated tools available (such as the AQoL<sup>4</sup> or EQ-5D<sup>5</sup>), which generally focus on health-related quality of life or health outcomes and which may not have been designed specifically for older people.

### *Service provider data collection*

Two service provider data collections were completed by CDC and CDRC providers: in July 2011 (covering the period 1 April to 30 June 2011) and in October 2011 (covering the period 1 July to 30 September 2011). The data collected related to CDC/CDRC participant characteristics, supports accessed and package expenditure for each participant, and development and ongoing costs incurred by CDC/CDRC providers.

### *Participant and provider interviews*

Semi-structured interviews were conducted with 51 CDC participants and carers of CDC participants, and 27 CDRC participants. Interviews were conducted in-person and by telephone.

Interviews were also conducted with 26 providers: 16 CDC providers and 10 CDRC providers. Interviews were conducted with a mix of providers across States/Territories, metropolitan and regional areas, small and large providers, and those targeting different special needs groups.

## **3.6 Challenges and limitations**

There were a number of limitations to the evaluation and challenges in conducting the evaluation:

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<sup>3</sup> The 'ICEpop CAPability measure for older people' (ICECAP-O) is a validated measure of wellbeing in older people. The ICECAP-O tool uses a definition of wellbeing which is broader than most other measurement tools (which focus on health and/or functional capability), and covers five attributes of wellbeing that were found to be important to older people in the UK: *Attachment* (love and friendship), *Security* (thinking about the future without concern), *Role* (doing things that make you feel valued), *Enjoyment* (enjoyment and pleasure), *Control* (independence). Further information is available at <http://www.icecap.bham.ac.uk/ICECAP-O/index.shtml> (accessed September 2011).

<sup>4</sup> Assessment of Quality of Life (AQoL) instruments measure health-related quality of life. Further information is available at, <http://www.aqol.com.au/> (accessed December 2011).

<sup>5</sup> EQ-5D is a standardised instrument for use as a measure of health outcome. Further information is available at <http://www.euroqol.org/> (accessed December 2011).

- *Timing of the evaluation*, bearing in mind the length of time the initiative had been in operation when the evaluation was being conducted
- The extent to which the evaluation could *attribute change or improvement* for participants (and carers of participants) *to the initiative* as distinct from change or improvement as a result of the *receipt of care and support*
- Utilising *data collection methods* appropriate for older people and their carers within the scope, timeframes and resources available for the evaluation
- Identifying the perspectives and experiences of participants in some *special needs groups* (as identified in the Aged Care Act), given their low representation in the CDC and CDRC participant groups.

#### *Timing of the evaluation and evaluation data collection*

The evaluation was undertaken less than 12 months after implementation of the CDC initiative.

The operationalisation of the initiative by providers was still evolving during this period, and providers were learning from their own experiences as well as the experiences of other providers to further develop their approach. A number of providers also experienced some delays in allocating packages to participants.

For many participants, their involvement in and experience of CDC and CDRC was limited and influenced by providers' evolving approach. Given most participants had been involved in the initiative for less than six months and a number less than three months at the time of the evaluation data collection activities, the benefits or impacts for participants from the initiative were unlikely to have been fully evident.

As a consequence of this, the evaluation and associated data collection placed more emphasis on the 'process' components of the evaluation – that is, how the CDC initiative had been implemented and operationalised, and the nature of participants' involvement in CDC – rather than on the outcomes of the initiative.

#### *Attributing change or improvement to the initiative*

One of the main methodological issues for this evaluation relates to the extent to which the evaluation could attribute change or improvement for participants to the initiative itself as distinct from change or improvement as a result of the receipt of care and support (or more care and support than they received previously). This is particularly relevant for participant *outcomes*, but also for their experiences and perspectives of the CDC initiative.

This is particularly relevant for CDRC participants, the majority of whom were not accessing supports or were utilising only low-level supports prior to commencing their CDC package. It is also relevant for CDC participants who had not received standard packaged care (CACP, EACH or EACHD) prior to CDC.

The evaluation approach attempted to explore this through participant interviews, as well as by undertaking comparisons of participant survey responses on three levels:

1. Comparing participants' perspectives, experiences and outcomes of CDC/CDRC with the perspectives, experiences and outcomes of a similar group of care recipients and carers receiving standard, non-CDC/CDRC packages (the comparison group).

2. Comparing participants' perspectives, experiences and outcomes at points in time when they were in receipt of a CDC/CDRC package compared with six months prior (when the majority did not have a CDC/CDRC package).
3. Comparing the perspectives, experiences and outcomes of CDC participants who had received a standard package prior to commencing a CDC package with those participants who did not receive a standard package.<sup>6</sup>

#### *Data collection methods*

The 'burden' of data collection on the CDC/CDRC participant groups and comparison groups was considered during the design phase of the evaluation, bearing in mind the fact that this group is older and frail. As noted above, the evaluation encompassed two different participant data collection methods: a paper-based survey and participant interviews.

The participant surveys – which were able to be completed by respondents in their own time – allowed the same data items to be collected from a large group of participants. However, detailed data was not able to be collected, and some groups were less likely to complete surveys than others (for example, people from an Aboriginal or Torres Strait Islander background, people who were homeless or at risk of homelessness, people living with dementia or cognitive impairment). The survey tools were designed to be simple, easy to read and understand, and of an appropriate length to gather the required data while minimising the burden on the respondent from completing the tool.

A number of interviews were also conducted, which allowed a much richer set of qualitative data to be collected (albeit from a small group of people). Conducting interviews also meant that those groups under-represented in the survey responses could be specifically targeted. The interviews were conducted in a semi-formal and semi-conversational way, using set questions as a guide.

#### *Identifying the experiences and impacts for people in special needs groups*

One of the challenges faced in conducting the evaluation was collecting sufficient data (through surveys or interviews) from participants from specific special needs groups (as defined in the Aged Care Act) to identify their perspectives and experiences of CDC and CDRC.

There were very small numbers of participants in the following special needs groups, which meant that no findings could be made in relation to these groups: people from an Aboriginal or Torres Strait Islander background, care-leavers, veterans and to some extent those who were previously homeless or at risk of being homeless.

While not a special needs group, it was also difficult to collect data from people living with dementia separately from carers of people living with dementia.

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<sup>6</sup> This comparison was not undertaken for CDRC participants given only a small number of participants were receiving NRCP services prior to commencing a CDRC package, and numbers were too small to do any meaningful analysis.

## 4 Profile of participants and the supports they accessed

### 4.1 Introduction

This chapter presents a profile of CDC and CDRC participants and the supports they accessed, based on data collected from CDC and CDRC providers as part of this evaluation. In particular, the chapter identifies:

- the characteristics of CDC and CDRC participants, and whether there were particular groups who were more or less likely to participate in CDC or CDRC than others
- the supports accessed by CDC and CDRC participants and the expenditure on those supports, and including the extent to which supports were provided in-house versus brokered or purchased from other support providers.

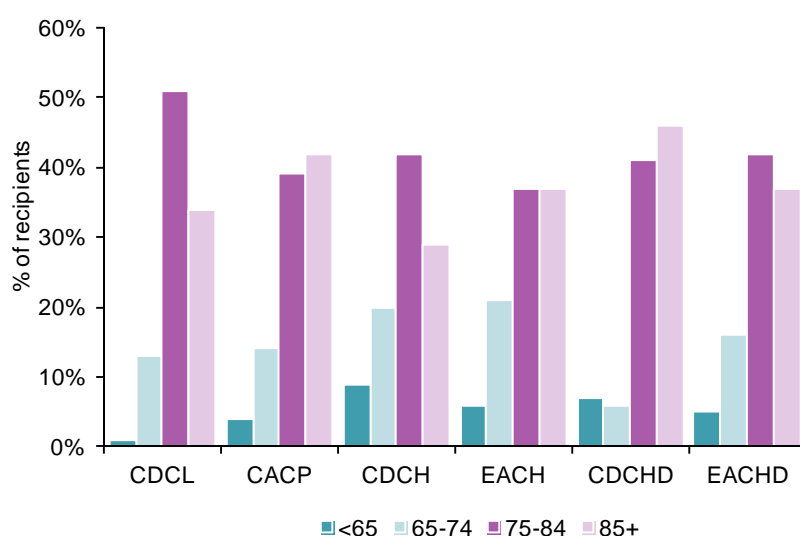
The data presented is sourced primarily from two provider data collections conducted as part of the evaluation.

Detailed data tables relating to participant characteristics and the supports they accessed are presented in Appendix B.

### 4.2 Profile of participants – CDC

The CDC participant group had a lesser proportion of participants aged 85+ and under 75 than the standard packaged care recipient group, with the majority aged 75-84. This was reflected in the CDCL group as well as the CDCH group (51 per cent and 42 per cent aged 75-84 respectively), though CDCHD participants were slightly older than the EACHD recipient group (46 per cent aged 85+ compared with 37 per cent of EACHD recipients). This is illustrated below.

*Figure 3: Age of CDC participants compared with standard packaged care recipients*



Source: 2<sup>nd</sup> CDC provider data collection (July-Sept 2011)

There was a reasonable representation of some special needs groups in the CDC participant group – in particular people from a culturally or linguistically diverse (CALD) background, people living in a rural or remote area, people who were financially or socially disadvantaged. There was also a reasonable representation of people who were homeless or at risk of homelessness among CDCL participants, which reflected the targeting of some CDCL packages specifically for this group.

There was a relatively low representation of Aboriginal and Torres Strait Islander people, however – and less for standard packaged care. Similarly, the proportion of CALD participants was also less than for standard packaged care (except for CDCHD).

This is illustrated in the table below.

*Table 1: Special needs group status – proportion of participants, CDC*

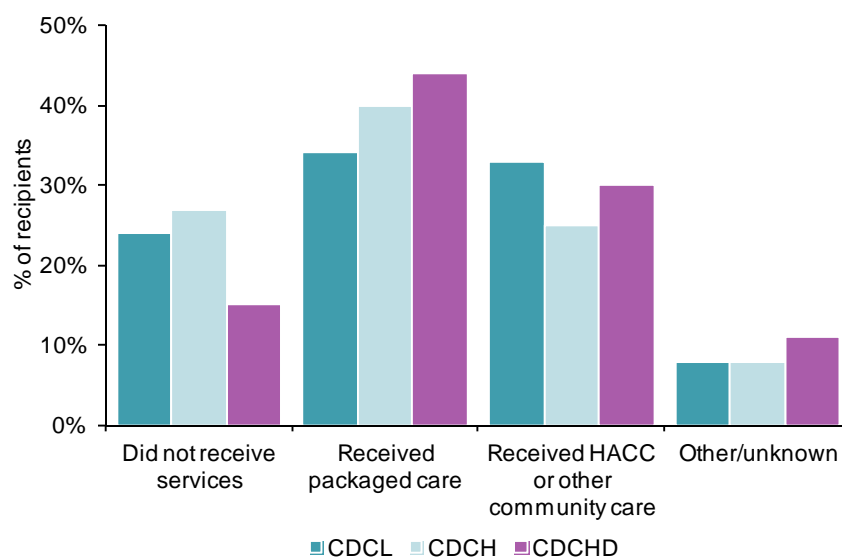
	CDCL	CDCH	CDCHD	Packaged care
Aboriginal or Torres Strait Islander	2%	2%	0%	3%
Culturally or linguistically diverse	15%	18%	24%	23%
Live in a rural/remote area	19%	12%	7%	...
Financially/socially disadvantaged	20%	18%	17%	...
Homeless or at risk of homelessness	5%	1%	0%	...
Veteran or spouse of a Veteran	2%	3%	2%	...
Care-leaver	0%	0%	0%	...

Source: 2<sup>nd</sup> CDC provider data collection (July-Sept 2011). Packaged care data relates to 2010-11, provided by the Department of Health and Ageing.

The proportion of participants who had received standard packaged care prior to commencing a CDC package was relatively low: 34 per cent of CDCL participants, 40 per cent of CDCH participants, and 44 per cent of CDCHD participants.

A reasonable proportion of participants (around 25 per cent for CDCL and CDCH) had no prior experience with community care prior to commencing CDC.

Figure 4: Service history prior to commencing on a CDC package



Source: 2<sup>nd</sup> CDC provider data collection (July-Sept 2011)

The number of participants exiting CDC was quite low – 12 per cent during the period July-September 2011. The majority of participants exiting moved into residential care. There were no noticeable differences across care levels.

Table 2: Number of participants exiting, by reason for exit – CDC

Reason for exit	CDCL	CDCH	CDCHD	Total
Died	1	6	1	8
Moved to residential aged care	13	6	4	23
Moved to standard (non-CDC) package	5	2	1	8
Other	2	2	0	4
<b>Total exits</b>	<b>21</b>	<b>16</b>	<b>6</b>	<b>43</b>
<i>Proportion of participants exiting</i>	<i>11%</i>	<i>13%</i>	<i>11%</i>	<i>12%</i>

Source: 2<sup>nd</sup> CDC provider data collection (July-Sept 2011)

## 4.3 Profile of supports and expenditure – CDC

### Breakdown of package expenditure

Package expenditure can be classified into three broad categories:

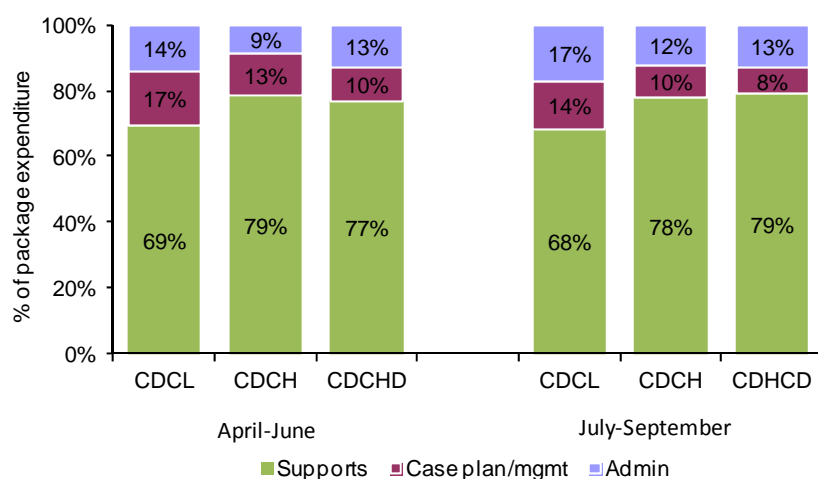
1. *Administration* – the fee charged by the CDC provider for administering the package.
2. *Care planning and management* – the fee charged by the CDC provider for care planning and support coordination and management.

3. *Supports* – expenditure on supports that a participant chose to access, including in-house (CDC provider) supports and brokered or purchased supports.

The figure below illustrates the breakdown of package expenditure for each of these three categories for each care level (for the April-June 2011 and July-September 2011 quarters). The figure shows that:

- administration accounted for between 12 per cent and 17 per cent of a CDC package, on average (using July-September quarter figures)
- care planning and management accounted for a further 8-14 per cent of package
- administration and care planning and management accounted for a larger proportion of a CDCL package (31 per cent combined in the July-September quarter) than for CDCH and CDCHD packages.

*Figure 5: Breakdown of CDC package expenditure*



Source: 1<sup>st</sup> and 2<sup>nd</sup> CDC provider data collections (April-June and July-Sept 2011)

#### *Scope of brokered supports*

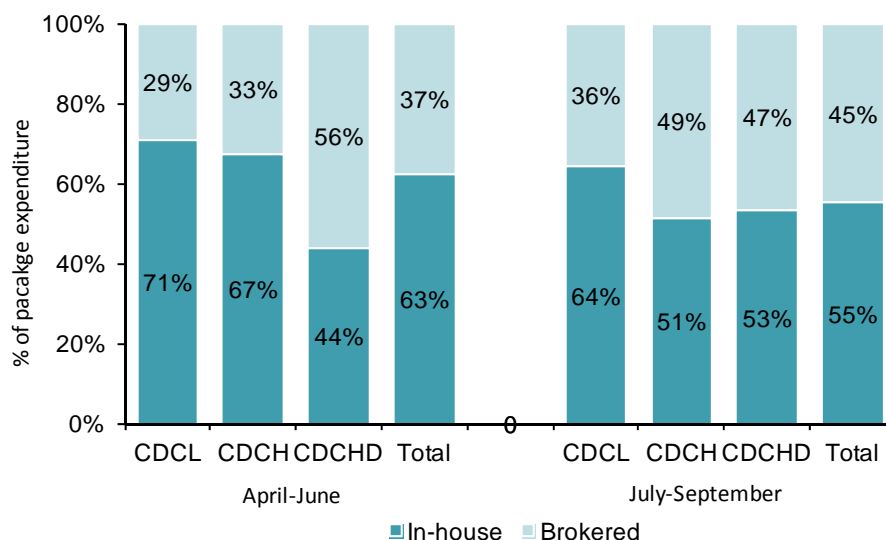
CDC participants can choose the providers of their supports, and many chose their CDC provider as their main support provider (and some their only support provider) – preferring one provider to deliver all or most of their supports.

The figure below illustrates the extent to which supports (excluding administration and care planning and management) were provided in-house by the CDC provider, versus brokered or purchased from other support providers on behalf of the CDC participant – based on reported expenditure on in-house and brokered services. As the figure illustrates, the majority of supports were provided in-house – 63 per cent of services in the April-June 2011 quarter, and 55 per cent in the July-September 2011 quarter.

There was a higher degree of in-house support provision for CDCL package recipients than for CDCH or CDCHD package recipients.

Interestingly, the proportion of in-house supports decreased between the two quarters, which indicates that participants were changing their support arrangements and choosing alternative providers after a period of ‘settling in’ to their package.

Figure 6: Proportion of CDC package expenditure – in-house vs. brokered supports



Excludes administration and care planning and management.

Source: 1<sup>st</sup> and 2<sup>nd</sup> CDC provider data collections (April-June and July-Sept 2011)

### Supports accessed

The tables below outline the most common types of supports accessed by CDC participants – by the number of participants accessing each type of support, and the level of package expenditure on each type of support.

The tables illustrate that:

- 64 per cent of CDCL participants accessed domestic assistance, which accounted for 29 per cent of CDCL package expenditure, on average. Other common supports accessed included support with activities of daily living (personal care) and social support.
- 75 per cent of CDCH participants accessed support with activities of daily living, and more than half accessed domestic assistance. Social support and nursing care were also common support types accessed.
- Support for with activities of daily living was also the most common support type accessed by CDCHD participants, and relatively high numbers of participants accessed nursing care and clinical care. A relatively high proportion of CDCHD package expenditure was also spent on leisure, interests and activities (11 per cent).

*Table 3: Top 5 types of support accessed by CDC participants, by proportion participants accessing these supports*

CDCL	% part	CDCH	% part	CDCHD	% part
1 Domestic assistance	64%	Activities of daily living	75%	Activities of daily living	52%
2 Activities of daily living	45%	Domestic assistance	52%	Domestic assistance	22%
3 Social support	30%	Social support	39%	Nursing care	22%
4 Nutrition, hydration and meal preparation	23%	Nursing care	31%	Social support	20%
5 Emotional support	18%	Nutrition, hydration and meal preparation	29%	Clinical care	20%

Excludes administration and care planning and management

Source: 2<sup>nd</sup> CDC provider data collection (July-Sept 2011)

*Table 4: Top 5 types of support accessed by CDC participants, by proportion of total package expenditure*

CDCL	% exp	CDCH	% exp	CDCHD	% exp
1 Domestic assistance	29%	Activities of daily living	36%	Activities of daily living	32%
2 Activities of daily living	25%	Social support	13%	Support for care recipients with cognitive impairment	17%
3 Social support	12%	Domestic assistance	11%	Social support	13%
4 Nutrition, hydration & meal preparation	7%	Nutrition, hydration & meal preparation	7%	Leisure, interests and activities	11%
5 Home maintenance	5%	Nursing care	4%	Domestic assistance	7%

Excludes administration and care planning and management

Source: 2<sup>nd</sup> CDC provider data collection (July-Sept 2011)

Appendix B contains further detail on the supports accessed by participants and expenditure on those supports, including data from the April-June 2011 quarter which has not been presented in this chapter.

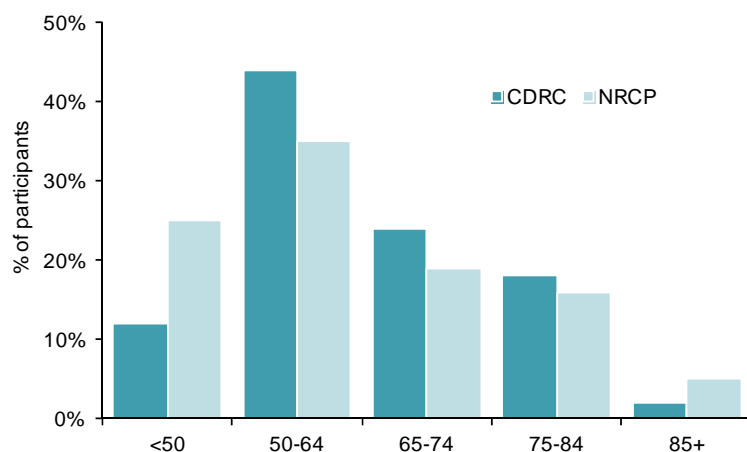
Note that no comparable data was available to compare supports accessed by CDC participants and standard packaged care recipients.

## 4.4 Profile of participants – CDRC

The CDRC participant group was slightly older than carers who access NRCP, with a greater proportion of participants aged 65 and over than the NRCP group. There were also fewer CDRC participants aged under 50 years than NRCP, with the majority of CDRC participants aged between 50 and 64 years (44 per cent).

This is largely consistent with providers' descriptions of their approaches to selecting CDRC participants – that is, carers with the interest in and capacity to self-direct and self-manage a package (generally adult daughters or sons caring for their parent, or younger spouses), and carers who were receiving low level support or no support prior to commencing their package.

Figure 7: CDRC and NRCP participants, by age



Source: 2<sup>nd</sup> CDRC provider data collection (July-Sept 2011), and NRCP 2011-Q1 data provided by the Department of Health and Ageing

In terms of participants from special needs groups, there were considerable numbers who were reported as financially or socially disadvantaged and who lived in a rural or remote area, though there was no NRCP data available to compare these proportions.

While participants from an Aboriginal and Torres Strait Islander background appeared quite low, this was broadly the same as carers' representation in the NRCP group. People from non-English speaking backgrounds, however, had much higher representation in the CDRC participant group than the NRCP group, though there was no evidence collected from CDRC providers to suggest that they were targeting people from CALD backgrounds.

There were relatively few participants who were reported as belonging to any other special needs group identified by the *Aged Care Act*.

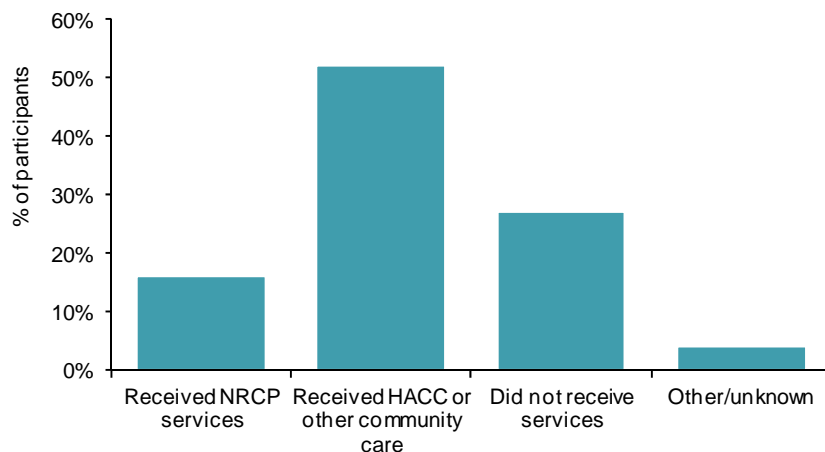
Table 5: CDRC participants by special needs group status

	CDRC	NRCP
Aboriginal or Torres Strait Islander	3%	3%
Culturally or linguistically diverse	16%	6%
Live in a rural/remote area	21%	na
Financially/socially disadvantaged	31%	na
Homeless or at risk of homelessness	1%	na
Veteran or spouse of a Veteran	1%	na
Care-leaver	1%	na

Source: 2<sup>nd</sup> CDRC provider data collection (July-Sept 2011), and NRCP 2011-Q1 data provided by the Department of Health and Ageing. 'na' indicates data was not available.

Only 16 per cent of CDRC participants were accessing NRCP services prior to commencing their CDRC package, although more than half of participants (or the person they cared for) were accessing low level home and community care (HACC) or other community care services.

Figure 8: CDRC participants' service status prior to commencing a CDRC package



Source: 2<sup>nd</sup> CDRC provider data collection (July-Sept 2011)

The number of exits reported for the April-June 2011 period was significantly higher than for the July-September period – as illustrated in the table below. When CDRC packages were originally approved, they were approved to operate for 12 months only – until the end of June 2011. Some CDRC providers interviewed indicated that they exited all of their CDRC participants at the end of June, and had been actively planning for this to occur (for example, by putting in place other supports for the care recipient such as a standard packaged care package). However, some providers stated that they were unaware that the packages had been extended, and hence exited participants unnecessarily. It is unclear whether this was related to an internal communication issue or a lack of adequate communication from the Department.

Exit data from the July-September period shows a different picture, with only 12 exits occurring. This represented 6 per cent of participants receiving a CDRC package during this period.

Table 6: Number of exits, by reason for exit – CDRC

Reason for exit	April-June	July-Sept
Care recipient died	11	1
Moved to another town/city/state	1	0
Care recipient moved to residential aged care	12	11
Care recipient moved to standard (non-CDRC) package	15	0
No longer needed package	9	0
Other	27	0
<b>Total exits</b>	<b>75</b>	<b>12</b>
<i>Proportion of participants exiting</i>	<i>44%</i>	<i>6%</i>

Source: 1<sup>st</sup> and 2<sup>nd</sup> CDRC provider data collections (April-June and July-Sept 2011)

## 4.5 Profile of supports and expenditure – CDRC

### *Breakdown of package expenditure*

Unlike CDC, CDRC providers received an allocation of \$2,000 per CDRC package to cover expenses associated with the administration of each respite package, client management and participation in the evaluation. This was separate to the CDRC package of \$4,200.

Like CDC, some providers also charged for care planning and management (or “case management and coordination” in terms of formal service type definitions).

Between 86 per cent and 91 per cent of total CDRC package reported expenditure was spent on supports for participants, with the remaining 9-14 per cent on case management and coordination.

This is illustrated in the table below:

*Table 7: Breakdown on CDRC package expenditure*

	Apr-June	July-Sept
<i>Proportion of reported package expenditure</i>		
Case management and coordination	9%	14%
Supports	91%	86%

Based on package expenditure reported by providers as part of the CDRC provider data collections. Excludes the \$2,000 administration allocation which does not form part of a package.

Source: 2<sup>nd</sup> CDRC provider data collection (July-Sept 2011)

### *Scope of brokered supports*

CDRC participants were able to choose the providers of their supports. However, unlike CDC providers, CDRC providers generally do not have significant in-house respite or other services, hence broker or purchase the majority of supports.

The table below illustrates the extent to which supports (excluding administration and case management and coordination) were provided in-house by the CDRC provider versus brokered or purchased from other support providers. As the table illustrates, the majority of supports were brokered or purchased – 77 per cent of services in the April-June 2011 quarter, and 66 per cent in the July-September 2011 quarter.<sup>7</sup>

*Table 8: Proportion of CDRC package expenditure – in-house vs. brokered supports*

	Apr-June	July-Sept
In-house supports	23%	34%
Brokered supports	77%	66%
	<b>100%</b>	<b>100%</b>

Excludes administration and care planning and management

Source: 2<sup>nd</sup> CDRC provider data collection (July-Sept 2011)

<sup>7</sup> Note that substantially less expenditure was reported in the July-September compared with the April-June quarter, and this may have impacted on the splits between in-house and brokered services.

### Supports accessed

The tables below outline the most common types of supports accessed by CDRC participants – by the number of participants accessing each type of support, and the level of package expenditure on each type of support.

The tables illustrate that:

- The majority of participants accessed assessment, information and counselling, support or advice, though these services did not account for a significant proportion of package expenditure.
- The most common types of respite accessed were in-home respite and individualised respite, with 48 per cent of participants accessing these types of respite, accounting for 30 per cent of expenditure. ‘Regular respite’ accounted for a further 14 per cent of expenditure.
- Only 9 per cent of participants accessed Commonwealth-funded residential respite, accounting for 7 per cent of package expenditure. This mainly reflects participants’ reluctance to use residential respite because of quality concerns and their level of discomfort with placing the person they care for in residential respite. In addition, the need to book residential respite in advance may have limited its use during the initial period that participants had a CDRC package, and some providers may not have allowed or encouraged participants to use residential respite because of uncertainty around whether package funds could be used for this purpose.

*Table 9: Top 5 types of support accessed by CDRC participants, by proportion participants accessing these supports, and by proportion of total package expenditure*

	% partic.		% exp	
1 Assessment	79%	In home respite	23%	
2 Information provision	63%	Regular respite care	14%	
3 Liaison/advice/support/ counselling	62%	Individualised respite	7%	
4 In home respite	32%	Commonwealth funded residential respite	7%	
5 Individualised respite	16%	Assessment	6%	
8 Commonwealth funded residential respite	9%			

Excludes administration and care planning and management

Source: 2<sup>nd</sup> CDRC provider data collection (July-Sept 2011)

Appendix B contains further detail on the supports accessed by participants and expenditure on those supports, including data from the April-June 2011 quarter which has not been presented in this chapter.

## 5 Implementation and operation of the initiative

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### 5.1 Introduction

This chapter considers issues relating to the implementation of the initiative by the Department and by providers, and the operationalisation of the initiative by providers – that is, how providers put the initiative into practice. In particular, it discusses the following evaluation questions:

1. *How effective were the CDC/CDRC initiation processes?* This encompasses program implementation by the Department, implementation of the initiative by providers, and recruitment and selection of CDC and CDRC participants.
2. *How effective were the CDC/CDRC planning processes?* This encompasses the different approaches to planning and budgeting used by providers, key elements of planning, and the degree to which planning was different for CDC and CDRC compared with standard packaged care and NRCP services.
3. *How effective was the delivery of CDC?* This encompasses approaches the coordination of packages and the extent to which participants self-managed their package.

The information presented in this chapter draws on the interviews with CDC and CDRC providers conducted as part of the evaluation, as well as interviews with Departmental representatives.

### 5.2 Provider motivations for participating in the initiative

The motivations of CDC providers and CDRC providers for participating in the initiative differed. For CDC providers, there were a number of reasons which influenced their decision to participate, including their commitment to person-centred approaches, their desire to respond to anticipated future consumer demand for increased choice and control, or their desire to access additional community aged care packages. Motivations were sometimes a combination of these factors.

For CDRC providers, the motivation to participate in the initiative was strongly linked to their identification of limitations in the traditional respite approach for some carers. CDRC providers saw the initiative as an opportunity to offer a more planned approach and secure additional funding for carers with ongoing, unmet respite needs. CDRC providers universally saw the initiative as an entirely new approach from traditional responses.

#### *Consumer-directed care providers*

There were a number of reasons why providers chose to participate in the initiative.

#### *Providers already had a strong commitment to person-centred approaches and saw CDC as consistent with their organisation's values and culture*

These providers spoke about consumer empowerment, choice and control being part of their organisational values and underlying approach to service delivery, and spoke of goals-focussed, strengths-based or enabling approaches to care planning and service delivery.

Several had prior experience with consumer-directed approaches in the disability field, and were already considering options for more consumer-directed approaches in their delivery of community aged care prior to the current initiative. They saw CDC as being significantly different from the standard packaged care approach because of its focus on the individual, its potential for more innovative use of funds to respond to individual goals, and the shift of control from provider to consumer.

Some were already trying to increase accountability and flexibility for existing clients within their standard packaged care approach prior to the CDC initiative, often in response to previous client complaints or frustration. Some already brokered a significant proportion of services as part of their standard care packages.

*"We saw CDC as a chance to free people from the constraints of having a pre-determined plan of pre-determined services. Having scope for more flexible use of funds would suit different types of people."*

CDC provider

*Providers saw CDC as an opportunity to do things differently, and wanted to be involved early in the testing and development of the approach*

*"There is going to be more demand for control by the baby boomers. We wanted to get in on the ground floor for that with this pilot."*

CDC provider

Generally, these providers recognised emerging demands for more choice and control from consumers and carers, and in particular from the 'baby boomer' generation. Their motivation for participating in the CDC initiative was more about being involved in this approach from the beginning and having the opportunity to shape and influence a new way of doing things.

While these providers typically had some understanding of CDC, they generally did not have any prior experience of CDC approaches prior to the initiative, nor did they have a strong consumer-directed or person-centred culture or approach in place in their organisation.

Providers tended to be relatively conventional in their approach to CDC, and the differences between CDC and standard packaged care varied widely among providers.

*Providers saw the initiative as an opportunity to access additional packages*

Some providers saw the initiative merely as a way to secure more funding for their organisation and to access more packages – to better meet demand for packaged care. These providers typically viewed CDC as another kind of packaged care, and generally provided CDC in more or less the same way as standard packaged care.

### ***Consumer-directed respite care providers***

All of the interviewed CDRC providers had identified significant limitations in the way current programs supported carers, including the inadequacy of providing only a short-term and emergency response to carers who had an ongoing need for respite, the limited availability of

formal respite and other supports and an inability to meet some carers' needs through the standard respite response (including carers in special needs groups and rural and remote locations).

Providers saw CDRC as an important and significant opportunity to take a *more planned approach to supporting carers*, and to *secure additional funding for carers* – which together would enable them to access the respites and other supports they needed, contribute to reducing carer stress, improving carer resilience and avoiding crises such as use of emergency respite, unplanned hospital admissions, and unplanned entry to residential care.

Providers also recognised the potential benefits of using a *coordinated 'case management' approach* for a number of carers (though recognising that the CDRC operational manual did not envisage an ongoing case management role in the CDRC model).

Unlike CDC providers, who tended to frame CDC in the context of and in comparison to standard packaged care, CDRC providers saw it as an entirely new approach. Importantly, they did not have preconceptions about how the model would operate or how the funds could be used, other than that they should be used to support carers in their caring role, and providers were open to exploring traditional and non-traditional support options.

## 5.3 Program implementation

### *Guidance and support from the Department*

CDC and CDRC providers consistently indicated that the level of guidance, communication and support offered by the Department during the implementation phase was less than optimal.

#### *Timing*

Several providers indicated that there was a gap between the allocation of places and the distribution of operating guidelines, and this in turn caused delays in the development of their own approach to CDC and the recruitment of participants.

A number of providers also noted that changes between the draft and final guidelines were not communicated in a timely way; many of them had already operationalised their places and put services in place by the time they were advised of changes to the guidelines. In some cases the changes required significant amendment to the processes and systems that providers had already put in place.

#### *Level of direction*

A number of providers appreciated the flexibility of the operating model, though the majority of those interviewed wanted more guidance and direction from the Department. Many CDC providers in particular identified a need for more definite guidance in some particular areas.<sup>8</sup>

A number of CDC providers also noted that the format, flow and terminology of the CDC guidelines<sup>9</sup> were similar to standard packaged care guidelines,<sup>10</sup> and that the CDC guidelines

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<sup>8</sup> Examples included using packaged funding for 'non-traditional' supports, services, or goods; roll-over funding; use of surpluses when a participant exited.

defer to the standard guidelines on several matters. This meant that the differences between CDC and standard packaged care were not always easy to see.<sup>11</sup> Providers also stated that it was not always clear where the standard guidelines should be consulted for additional information.

#### *Ongoing support for providers*

The Department provided ongoing support to providers through a telephone 'helpdesk', and produced a series of frequently asked questions which were published on the Department's website.<sup>12</sup> However, it appeared that some providers were not aware of or did not utilise these supports.

Beyond the issues of timing and guidelines, CDC and CDRC providers also indicated that they would have preferred more *proactive* support from the Department during the implementation. Providers suggested that some initial training or face-to-face briefings by the Department would have been useful, as well as more regular information exchange and discussion with other providers and the Department focussing on building providers' capability to be consumer-directed (rather than merely to disseminate information).

*"The Department just gave us the guidelines and the dollars and said 'off you go'."*

CDC provider

In lieu of formal, proactive support and training from the Department, providers relied on their own networks for support and information about CDC and CDRC, including discussions with other providers with more experience of CDC. While this proved a suitable form of support, some providers were concerned that the perceived lack of direction from the Department led to inconsistent application of CDC and CDRC across providers and jurisdictions, which in turn affected consumer experiences of CDC and CDRC.

## 5.4 Provider implementation

#### *Development of an organisation's approach*

Providers undertook a number of activities relating to the development and set-up of their organisation's approach to CDC/CDRC, including:

- determining how their approach would operate in practice
- identifying how to market their packages and recruit suitable participants
- engaging with other stakeholders such as ACATs and brokered service providers

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<sup>9</sup> *Consumer Directed Care in Australian Government Packaged Care Programs 2010-2012 Operational Manual*

<sup>10</sup> *The Community Packaged Care Guidelines 2011*

<sup>11</sup> Notably this was not raised as an issue by CDRC providers

<sup>12</sup> <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-cpb-cdc-faq.htm>, accessed January 2012.

- developing participant information, participant agreements and budgeting templates
- identifying the internal systems changes or developments required to support the operation of CDC/CDRC.

The short-period of time in which the initiative was rolled-out by the Department was identified as a significant issue for many providers. Providers stated there was insufficient time between receiving notification from the Department that they had been successful in their application for CDC/CDRC places, and when the places had to be operationalised. As a result, many providers felt that their development work and implementation was rushed, and there were considerable delays in some providers allocating their packages to participants.

#### *Staff selection, development and training*

CDC and CDRC providers relied on highly experienced, existing staff to implement their organisation's approach, and manage the participant selection, planning and support coordination. Usually, these were manager-level staff or senior coordinators who had been involved in the development of their CDC model.

A small number of providers undertook specific recruitment for coordinator/case worker positions. During the pilot period, providers tended to use one or two coordinators to work specifically on all aspects on CDC or CDRC (including the administration components), rather than a larger number of coordinators each having one or two CDC or CDRC participants amongst a wider standard care client load.

Providers identified a number of key skills and attributes required for CDC and CDRC coordinators – outlined in the box below.

#### *Skills and attributes of coordinators identified by providers*

- Skills and experience in individualised assessment and goal-based planning
- Skills in client capacity building and case management
- Knowledge of aged care or respite, but no preconceived ideas about what community aged care or respite 'is' or 'looks like' – an ability to 'think outside of the box'
- Financial skills, both in terms of managing individual budgets and helping clients to understand their budget statements (this is quite different to the standard packaged care approach)
- Commitment to client empowerment and self-determination.

While most providers selected existing coordinators with the best mix of skills and attributes to work on CDC and CDRC, coordinators generally did not have all of the necessary skills and attributes required, and some training and skills development was needed.

There was a considerable degree of informal and on-the-job training and skills development for coordinators, rather than specific formal training. This included:

- involvement of coordinators in the development of the organisation's approach and application of CDC and CDRC
- understanding the language and philosophy of consumer-direction, generally through sector-initiated information sessions, conferences and research

- one-on-one support from managers relating to interpretation and application of the guidelines or the organisation's approach
- specific skills development – particularly related to support around budgeting and budget reporting
- sharing experiences of CDC with other providers through provider networks.

There was little evidence of training in CDC/CDRC approaches for direct support workers employed by providers or by organisations from which they brokered services.

#### *Differences in implementation and operation between providers*

There were variations in the way CDC in particular was implemented and operated across different providers, and the degree to which CDC was different from standard packaged care. Variations were particularly evident in planning processes, in providers' degree of flexibility around the range and choice of services offered to participants, and in providers' openness to innovative or non-traditional services.

These variations related to differences in:

- the extent to which CDC was understood by providers as being 'different' from standard packaged care
- the extent to which providers were already flexible or person-centred in their approach
- the provider's degree of comfort with the CDC model and their assessment of the 'risk' to them of giving more control to clients
- their motivation for applying for CDC (to gain access to additional packages, or to test a way to do things differently).

The degree to which providers were already flexible and person-centred in their approach influenced the degree of change that was needed for them to implement CDC. Those who were less flexible or person-centred and/or who had less experience of consumer direction and person-centred approaches, appeared to face greater challenges in operationalising a form of CDC which was different from standard packaged care.

The manager(s) or project officer(s) responsible for designing and implementing CDC appeared to be a key factor that influenced a provider's capacity to embrace the self-direction 'spirit' of CDC, and to implement the model in a way which distinguished it from standard packaged care. Their personal level of commitment to the principles of CDC and the extent to which they saw CDC as an opportunity to do things differently (as opposed to an opportunity for additional packages) was an important enabler for making CDC work.

### Key points – Program and provider implementation

#### *Support and guidance from the Department*

- Many providers would have appreciated some initial training or a help desk function by the Department, earlier provision of operating guidelines, and better communication of changes between draft and final guidelines.
- Some providers appreciated the flexibility of the operating guidelines during the pilot period, but would have liked clarification about a number of specific program issues.

#### *Provider implementation*

- Providers needed more time to operationalise CDC and CDRC and to develop their approach.
- Providers relied on the skills and experience of existing staff to develop and implement CDC and CDRC. There were specific skills and attributes identified for CDC and CDRC care coordinators: relationship building and case management skills, assessment skills, financial management skills, knowledge of community aged care, respite and wider social services, a commitment to client empowerment and self-determination, and an ability to think laterally and ‘outside the box’. A lack of preconceptions about what community care or respite “is” or “looks like” was also important.
- While providers selected existing coordinators with the best mix of skills and attributes to work on CDC and CDRC, coordinators generally did not have all of the necessary skills and attributes required, and some training and skills development was needed.
- Coordinators’ skills and knowledge were developed primarily through informal training and on-the-job experience – predominantly by being involved in the development of the organisation’s own approach to CDC/CDRC, one-on-one support from managers, provider and industry-led initiatives, and specific training to develop new skills (such as budgeting and budget management).

## 5.5 Participant selection

### *Selection of CDC participants*

Many providers felt that existing clients with experience of standard packaged care would be best placed to participate in CDC, and first sought to approach existing clients to participate in CDC. A limited number of providers did this through a mass mail-out to all clients inviting them to elect to participate in CDC, but the majority used a more targeted approach by using their coordinators to identify clients they thought might be interested and have capacity to self-direct.

### *Characteristics of participants*

Providers looked for certain characteristics in potential CDC participants.

For high care categories, the presence of a carer (or a family member actively involved in the person’s life) was considered to be a critical enabler for a package. Carers who were under very high levels of stress, or who had their own health problems, at the time of entry were generally not considered suitable. Carers who asked a lot of questions, expressed ideas about how they wanted care and services delivered, or showed some interest in the financial aspects of a package were considered more suitable.

For low care participants, providers looked to people who they thought had sufficient capacity and who might have an interest in self-direction. This included those who may have expressed dissatisfaction with some aspect of their package in the past.

Some providers also looked at factors such as a person's previous work history or education levels in identifying potential participants – using this as an indication of their capacity to be actively involved and self-directed aspects of their package and support arrangements.

#### *Level of interest from existing packaged care clients*

Providers reported relatively low levels of interest from existing packaged care clients, especially at the low care level. Many existing clients did not see any additional benefit to them from having a package in terms of the types or level of supports they might be able to access, and many were satisfied with their existing care arrangements. Many existing clients also felt unable or were unwilling to become more involved in their care planning and decision-making and a number were concerned about the potential burden of being involved. A number were also concerned about the pilot nature of the initiative.

Providers had more success in recruiting existing EACH and EACHD clients to CDC, particularly clients who had a younger carer (usually an adult daughter or younger spouse). These carers were attracted to having more control and to take on coordination themselves (to free up funds for more care hours), or were attracted to the potential for more flexible service delivery.

*"We thought there would be more demand for CDCL. We could fill 10, 20 more CDCH places tomorrow, because the carers want it, but people don't see the benefits at the low level – they'd rather stay on a CACP."*

CDC provider

*"CDC is a model we want people to want, but people don't really want it yet."*

CDC provider

#### *Targeting new packaged care clients*

Where providers were unable to recruit sufficient existing clients, they looked to fill their CDC places with new packaged care clients.

A number of providers also specifically targeted new clients first – either newly referred to them, or on a waiting list for a package. New clients were identified by the provider as part of their initial assessment and care planning process, or based on an indication from an ACAT of a person's potential suitability for CDC. If a person demonstrated an interest in the budget details, appeared to have the capacity and interest in self-direction, or indicated a desire for certain 'non-traditional' responses, then they would be referred to the CDC coordinator who would then discuss options for a CDC package with them. For some participants who had not received packaged care before, the CDC package was the only package available.

A small number of clients directly approached providers about CDC. Typically they were younger carers of CDCH or CDCHD participants who were familiar with the CDC approach and wanted more flexible service delivery, and more control over their package budget. These carers were also typically dissatisfied with their experience of traditional packaged care.

### *Role of ACATs*

Providers did not see a role for ACATs in determining whether people were appropriate for CDC – this was a decision that providers made themselves – though many providers relied on ACATs to provide an *indication* of who might be appropriate for CDC.

Some ACATs specifically referred people to CDC providers rather than non-CDC providers where they thought a person might be appropriate for CDC, though left the decision as to whether the person received a CDC package or a standard package to the provider. Where providers had difficulty filling their CDC packages, or where they were targeting specific special needs groups (such as people who were homeless or at risk of homelessness), they relied more heavily on ACATs to identify potential participants.

However, initially ACATs had little or no understanding of CDC and were not in a position to indicate who might be appropriate for CDC. A number of providers spent time with ACATs explaining the CDC model and what they expected from ACATs regarding CDC – something which a number of providers considered should have been the role of the Department.

### *Selection of CDRC participants*

CDRC providers tended to target potential participants who were already known to the CRCC, rather than seeking to recruit through a mass mail-out or marketing. Providers sought to target CDRC packages to those carers who seemed to be the most in need and who might realise the most benefit from the CDRC approach, as well as those who they thought had the capacity and the interest in directing their package:

- high users of emergency and other respite services
- those with limited access to ‘traditional’ respite services
- those with limited or no access to other formal and informal supports, including community aged care packages
- carers of people living with dementia or disability
- younger carers of frail older people with capacity and interest to self-direct.

Some providers also targeted specific groups, such as Aboriginal and Torres Strait Islander carers, culturally and linguistically diverse carers, and carers of people who frequently attended hospital emergency departments, and carers in same-sex relationships.

Generally, there was a high level of interest in CDRC from potential participants, and almost all of the people that providers approached agreed to participate in CDRC. Often, they expressed profound surprise and delight at having a package of funds made available to them. For many CDRC participants, this was the first time that someone had talked to them about their needs, goals and desires, rather than talking about the care recipients’ needs.

*“They felt like they’d won the lottery when we told them about the package. Some of them weren’t sure what to do with it at first – they didn’t understand it was about them, not just the care recipient – but they were thrilled to have it.”*

CDRC provider

Some carers told providers they were happy to continue making occasional use of respite when they needed it, and were uninterested in having planned and regular respite, or concerned about the burden a CDRC package might create. There were also a number of carers who refused to participate because of the pilot and short-term nature of the program (noting that at the time most participants were being recruited, CDRC packages had been approved only to the end of June 2011).

Some providers experienced difficulty attracting and retaining Aboriginal and Torres Strait Islander carers for CDRC. This was attributed to a variety of factors: lack of time to build rapport and understanding about CDRC with Aboriginal and Torres Strait Islander communities, use of assessment and planning approaches that were perhaps not culturally appropriate, pressure on carers to share CDRC resources with the wider community (humbugging), and, in the case of Aboriginal and Torres Strait Islander carers living in remote areas, various difficulties presented by distance and remoteness.

#### Key points – Participant selection

- Providers used a mix of approaches when selecting CDC participants, with some targeting existing packaged care clients and others new clients. A ‘targeted’ approach to participant selection was more effective than an open approach (such as a mass mail-out).
- In selecting participants, providers commonly targeted those with a carer or a family member actively involved in the older person’s life (for CDCH and CDCHD). For low care participants, providers looked to people who they thought had sufficient capacity and who might have an interest in self-direction. Providers also looked at a person’s capacity to be actively involved and self-direct aspects of their package and support arrangements.
- The level of interest in CDC was lower than providers expected. There was a low level of interest in CDCL packages from existing CACP clients, and to some extent from new clients. There was more interest from existing EACH and EACHD clients and their carers in CDCH and CDCHD packages.
- There was a moderate level of interest from new clients in CDC, though a number of new clients chose a standard package over a CDC package. In some cases, the CDC package was the only package available.
- CDRC providers tended to target potential participants who were already known to them, and who were considered a ‘priority’ (such as carers under stress or who had little or no access to formal supports), and who had the ‘capacity’ to participate in CDRC. A number of providers targeted younger carers who they considered were more appropriate for CDRC than older carers.
- There was a considerable level of interest in CDRC from those approached, with very few declining to participate.

## 5.6 Planning

*Care planning* refers to initial and ongoing assessment, planning and management of care by CDC and CDRC providers, with the involvement of the care recipient and their carer. Under the guidelines, this should be documented in a care plan.

*Budget planning* refers to the development of an individual budget for the provision and purchase of the care, services and materials in accordance with the care plan. The budget also

includes provision for administration fees, and contingency funds to be set aside for any changes in participant circumstances (CDC only).

The planning processes adopted by CDC and CDRC providers were very similar.

### *Eligibility and consent*

Following a determination of potential eligibility by a provider, the initial planning processes were characterised by a series of in-person and phone meetings between the coordinator or case worker, the participant, the participant's carer (for CDC) or the person they were caring for (for CDRC), and often also other family and care network members. Typically, discussion held in the initiation stage (relating to how CDC or CDRC would work, participant's responsibilities, and high-level discussion about needs and goals) would then merge into the planning stage for those people who agreed to participate.

In most cases, consent was documented in a written agreement between the participant and provider. The provider then undertook a needs assessment.

### *Needs assessment and planning*

Providers used a wide variety of tools to assist in needs assessment. In some cases, this included some form of self-assessment. It was at this point that the assessment and planning processes tended to merge, and discussions about the participants' goals and objectives would merge into discussions about potential support options and likely budget implications.

In many cases there were a number of meetings or discussions, depending on the participants' and carers' insights to their care needs, their ability to identify and articulate goals, and their capacity to engage with self-direction.

Those discussions were usually turned into a draft care plan, perhaps with some budget options, for the participant and carer to consider. Once the plan and budget were agreed, the provider would put the supports in place and usually provide some mentoring support to the participant and carer (i.e. how to use the service confirmation forms, how to check in with the provider, how to manage problems). In most cases, providers reported that a documented care plan and budget was given to the participant or carer, but this did not occur in all cases. Some providers indicated that they documented care plans in client file notes. In many cases (though not all), the participant were given a copy of the final care plan and budget documents.

In some cases, planning was able to be completed in a single meeting, though typically it occurred over a series of meetings.

While this broad approach to assessment and planning was generally consistent across CDC and CDRC providers, there were variations in the process. For CDC, there were two approaches to planning: either *goal-based* or *menu-based*, which are described below.

***Goal-based planning*** focussed on identifying the goals, desires and objectives of the participant and carer, before then looking to identify possible support options.

For CDC, this approach used the ACAT assessment as documented in the Aged Care Client Record as a starting point, generally supplemented with other assessments that explored the participant and carer's interests, preferences and social activities. Tools such as self-assessments, the International Wellbeing Group's Personal Wellbeing Index, and resilience care plans – and variants thereof – were used by several providers.

CDRC providers used tools including adapted versions of the Carer Eligibility and Needs Assessment (CENA) tool, the Zarit Carer Burden scale, and guiding questions from the Carer Strain Index.

Providers did not consider that a common assessment tool would be useful at this point – they liked the ability to ‘mix and match’ tools, and to try out different approaches.

**Menu-based planning** focussed on the ACAT needs assessment and provision of a list of available supports, providers and price list to the participant or carer. It was particularly used with CDCL participants, by CDC providers who used the ‘enhanced choice’ service model described earlier in this chapter, and by CDC providers who tended to use more in-house services than brokered.

The level of information provided about available service providers varied considerably: some CDC providers maintained extensive lists of all available service providers and their prices, and made these available to participants and carers.

Others used a ‘default’ approach to use in-house services, but would engage a specific service provider or support worker based on the individual participant’s wishes (for example, if they wanted a support worker that spoke their native language, or one they had previously used).

*“Everything is on the table –  
whatever sustains the carer.”*

CDRC provider

The *goal-based approach* was more individualised and allowed more scope for innovative use of the package funds, and was clearly a different approach to the standard packaged care approach. The *menu-based approach* was easy for some participants and carers to understand (particularly those with no prior experience of community care), and was easier and less-time consuming to complete. However, the approach tended to focus on pre-defined service types and allowed less scope for innovation.

For CDRC providers the planning process was completely new from that used in NRCP. The approach they took was predominantly that of goal-based planning rather than menu-based. While traditional respite services formed a significant part of most care plans, they were always seen as only one aspect of ‘respite’ and participants were encouraged to consider a wide range of options which supported them in their caring role.

While all CDC and CDRC providers indicated that some form of care planning occurred, there was some inconsistency in documenting the care plan. The majority of providers gave copies of the plan to participants, whereas a small number indicated that they either did not give copies to participants and merely placed them in the participant files, or did not produce a formal care plan but documented the planning discussions in file notes.

### Examples of instruments used to support goal-based planning

#### *Self-assessment questionnaire*

A provider had designed a questionnaire which participants completed themselves prior to undertaking the planning component of CDC. The questionnaire asks participants to consider and describe various aspects of their life, needs, and circumstances through a series of open questions, including:

- their main reason for seeking assistance
- what works well and not so well for them
- what level of informal support they have
- what is important to them in life
- what stops them doing what they want to do.

The questionnaire also asks a series of questions about tasks and activities (personal care, social activities, transport, cleaning etc.) that the person considers they can do themselves, ones they already have help with, and ones they feel they need help with. It is used alongside the scaled Personal Wellbeing Index.<sup>13</sup>

#### *Resilience self assessment tool and care plan*

The Resilience self-assessment tool is completed by participants before the planning process commences, and asks participants to rate their level of *happiness or satisfaction* with seven different life areas, and the level of *importance* they place on each of these areas. The tool also asks participants to indicate what they like to achieve, or what they need help with, for each of the life areas, as well as an overall goal for their plan. The life areas are:

- health and wellness
- physical environment
- learning, leisure and interests
- mobility and transport
- community groups and involvement
- relationships and family
- managing finances.

The completed tool is used as a basis for developing a Resilience Care Plan, which identifies the participant's goals for each of the life areas and agreed interventions. The Plan and progress towards meeting each goal is regularly monitored.

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<sup>13</sup> See <http://www.deakin.edu.au/research/acqol/instruments/wellbeing-index/> for a description of the Personal Wellbeing Index.

#### *Social and leisure interests questionnaire*

This simple questionnaire seeks to gain insight into things that are important to the person, and/or activities they enjoy. The tool does not focus on the person's health status or need for assistance; rather, it focuses on their interests and hobbies. Questions explore aspects such as:

- the person's general life history and employment history
- particular household tasks and routines the person likes to do
- activities and hobbies the person has found important or enjoyable over their lifetime
- people who are special in their life
- cultural and spiritual special events
- their preferences for group or one-on-one interactions.

The results are used to assist in the care planning process.

#### **Key points – Planning**

- The initial planning phase was generally intensive, involving several in-person visits, provision of information, development of a written care plan, identification of options for care and service providers, drafting and finalisation of budget, and establishment of the package of care and services. Duration and intensity of this phase tended to vary depending on the capacity of the individual participant or carer, rather than on the basis of their care level or special needs group status.
- Assessment and planning was either goal-based or menu-based. The level of information and options given to participants and consumers, and the scope for innovative use of funds, varied markedly depending on the provider.
- There was inconsistency in the use of documented care plans.

## **5.7 Delivery and coordination**

Delivery and coordination refers to the organisation, delivery and monitoring of supports once the care plan had been put into place. It included the coordination and delivery of care and services by in-house and brokered providers, purchase of other equipment and other items, quality assurance and monitoring, confirmation of services received and payment of invoices, budget management and reporting, and review of the care plan.

### ***Models of coordination***

Providers used a mix of approaches for delivery and coordination of CDC and CDRC. The evaluation identified four broad models of coordination.

Providers developed these models based on their prior experience (both with aged care and other community services, particularly individual disability supports, for those providers involved in delivering other community services), research on the operation of other CDC models, and consumer feedback and input.

Providers used a range of direct and indirect approaches to include consumer feedback in their coordination model design, including focus groups, reference groups and historic feedback (including formal satisfaction surveys) from existing clients.

### *1. Progressive or tiered model*

Under this model, there are up to three levels of CDC. Each level has a fixed administration fee, but the proportion of the budget for support coordination and management compared with delivery of supports (brokered or in-house) varies depending on the level of participant or carer control.

At the initial level, there are more funds for care planning and management to cover the initial care assessment and planning, arranging and coordinating supports, and building the participant or carer's capacity to self-direct their package over time. As the participant or carer's capacity increases, they are able to take on more responsibility and progress to the next level of control and self-direction. The proportion of the budget allocated to the CDC provider for care planning and management decreases, and the proportion available to the participant to purchase supports and other goods and services increases. The coordinator is still involved, but primarily in a support role. At the third level, the participant or carer takes on full responsibility for care planning and management.

There are generally no timeframes set for progression between tiers – it will vary based on the individual – but the expectation is that all participants or carers can progress to higher tier levels (with the exception of CDCHD participants who all received some case management in accordance with the guidelines).

This model was used by a limited number of CDC providers. It appeared to be the most sophisticated and transparent model, providing a clear pathway for clients through the increasing levels of control (though most participants tended to take longer than anticipated to progress through the levels).

This model was not used by CDRC providers.

### *2. Capacity building or mentoring model*

Under this model, the initial care planning and management phase is relatively intensive and focuses on putting the supports in place and building the capacity and confidence of the participant or carer to self-direct. Over a period of time, usually a few months, the support coordination and management tapers-off and the participant or carer takes on more coordination responsibilities. The period of initial mentoring varies depending on the individual, but the individual's capacity to self-direct is a key factor that is considered in the initial CDC assessment.

The proportion of package funds available for supports does not increase as provider care planning and management decreases. Additional care planning and management can be purchased if the participant or carer wants some ongoing or periodic support. As with the progressive/tiered model, there is always a case management component in CDCHD. Under this model the provider retains responsibility for administration.

This model was used more widely by CDC providers than the progressive/tiered model, and it had similar advantages in terms of transparency and clarity of client pathways. From a provider

perspective the main disadvantage was that the cost of the initial intensive care planning was not always recouped from package budgets.

This model was also used by some CDRC providers.

### *3. 'DIY' optional model*

Under this model, participants are able to choose a 'DIY' support coordination and management model, where they undertake all ongoing support coordination and management tasks more or less immediately, with some initial training and support in budget monitoring, use of timesheets, scheduling of service providers by the CDC provider. Participants can also choose to purchase additional care planning and management from the CDC provider. Fees for care planning and management are based on the costs of care planning and management for different package levels.

This model was intended for participants who were receiving a standard care package prior to their CDC package, and who might be looking for additional support hours or funds and had capacity to self-direct. As with the progressive and mentoring models, the provider retains responsibility for administration, and a component of case management remains embedded in CDCHD.

This model was not widely used by CDC or CDRC providers. Where it was used, it particularly appealed to younger carers who wanted to take an active role in the support coordination and management, but who still liked having the 'safety net' of access to additional support coordination and management if needed.

### *4. Enhanced choice model*

This appeared to be the predominant model used by CDC and CDRC providers.

This model does not differentiate between the provider's administration and care planning and management functions. The extent to which participants or carers coordinate their supports varies between individuals, though providers retain a significant degree of responsibility for support coordination (particularly where the majority of services were provided in-house by the CDC provider rather than brokered). The major difference for participants or carers compared with standard packaged care is that they have more choice, more flexibility in service delivery, and an ability to accrue surpluses for additional expenditure. The actual level of control participants or carers exercised under this model was limited in practice, however.

A number of providers intended to implement one of the first three approaches, but in practice defaulted to the 'enhanced choice' approach – usually because the time needed to build participants' capacity and confidence to self-direct was greater than anticipated.

## *Delivery of supports*

### *Use of in-house and brokered services*

Providers indicated that most CDC participants were happy to access all or most of their supports from a single provider (usually the CDC provider). While providers would broker services from another agency where specifically requested by a participant, it was often incumbent on the participant to know what they wanted (i.e. a specific support worker, or a specific language ability). However, the CDC providers have an incentive to encourage clients to

use their own in-house services, and some CDC providers had an internal organisational policy to increase their in-house services and decrease their use of brokered services.

For many participants, the decision to use the provider's in-house services was based on price, as the cost of brokered services was often higher, particularly in areas where there was limited choice and if the CDC provider charged an additional fee for arranging the brokered services.

One CDC provider also suggested that brokered services were sometimes more expensive because of opportunistic price gouging. They reported that, on several occasions, they had approached local agencies about brokering services in response to specific participant requests, and the agencies took the opportunity to inflate their prices for the quoted services because they knew the participant had specifically requested them. In each of those cases, however, the client elected to use the less expensive in-house services once the options and prices were put to them.

It was not clear the extent to which participants were actively 'encouraged' to use in-house services, but it is clear that the detail and level of information given to participants about brokered providers differed between CDC providers. Some providers gave participants detailed information and price lists as a matter of course; others only provided the information verbally or on request.

In the case of CDRC, the majority of services were brokered.

#### *Use of informal services*

One of the conflicts faced by providers was where a participant or carer requested the services of a person known to them (such as an independent support worker, a member of their extended family or neighbour, a private cleaner, a handyman, or a preferred taxi company or driver).

Because CDC providers were accountable for the quality and safety of supports provided with CDC and CDRC funds, most CDC providers required that support providers either be approved aged care providers, or that they enter into a service agreement with the CDC provider. Entering into a service agreement usually requires an ABN, workers' compensation and public liability insurance, and a criminal history check for support workers employed by the organisation.

Furthermore, the CDC and CDRC operating guidelines allow the use of informal workers – excluding family members – so long as usual requirements for workers' compensation, superannuation and insurance were met.

Some people were unable or unwilling to meet these requirements, which meant that the CDC or CDRC provider was unable to engage them to deliver supports to a person on the package. This effectively meant some participants were prevented from using their preferred provider, despite the policy intention of CDC and CDRC (as indicated in the operating manual) to allow funds to be used to engage informal services.

There were some cases where a CDC package was used to employ a family member or neighbour to deliver care. The way in which this was done was to have the family member become an employee or contractor of the CDC provider (or another agency).

## Management of budgets

Approaches to managing the individual budget were quite different for CDC and CDRC. The key difference was that CDC providers were able to determine package allocations and administration fees, while both the CDRC package allocation and administration fee was fixed.

### *Determining the size of a CDC package*

The CDC operational manual clearly indicates that providers should *'assess the needs of the care recipient and carer together to develop a budget for the care recipient based on those needs'*, with the proviso that *'care recipients with the same or similar needs should receive comparable allocations of budgets and services'*. The manual specifically states that individual budgets need not exactly match the subsidy income paid to the provider for that client.

Despite this flexibility, in almost all cases providers chose to set their CDC package amounts at the relevant subsidy levels. Many felt it was important, from a transparency perspective, to set the package allocation at the subsidy levels because the amounts were publicly available and potentially known to participants.

Some providers thought it was important to have the flexibility to modify the individual package allocations according to participant need, but still used the subsidy levels to determine package allocations (often because they were unaware that they were able to change it, or because they had already set their package allocations by the time the revised guidelines were distributed to them). That the majority of providers chose not to adjust package allocations was particularly interesting given the concerns several raised about not being able to 'pool' CDC subsidy funds for distribution based on variable client need (something which commonly occurs with standard packaged care income).

Even when providers were aware that they could determine package amounts themselves, many highlighted the potential difficulty in determining an appropriate package level for a participant. Planning discussions with participants and carers were often framed around the pre-determined package amount (with participants and carers being aware of the package amount from the start). Hence there was little scope to modify the package amount during or following the planning discussions and the participant or carer had come to see the amount as "their budget". Having the ability to accrue and expend individual budget surpluses was a particular attraction of CDC for many participants and carers, and so it would have been a difficult negotiation for a provider to then effectively reduce or remove that potential surplus by reallocating some of "their" budget.

An alternative approach – one closer to that described in the CDC manual – would be to work with a participant to determine their needs and goals (using a goals-based process) without discussing the size of the package, and following this discussion the provider could either estimate the cost of the package, or determine the size of the package using their own pre-determined categories or levels. However, providers noted that 'costing' a package would be more time-consuming and may result in inequities across providers, although they also noted that it could result in the most appropriate package allocation for each participant.

A predominant view among providers was that the three package levels did not take into account the range of needs among participants, and in particular that the gap between a CDCL package (with a subsidy level of \$13,248 per annum in 2010-11) and a CDCH package (subsidy

level of \$43,982 per annum in 2010-11) was too great. This was also a common concern for standard packages generally, however, and does not relate specifically to CDC.

#### *Determining the size of a CDRC package*

The size of a CDRC package was set by the Department at \$4,200 per package per annum. There was no evidence that providers deviated from this amount.

A number of CDRC providers were dissatisfied with their inability to modify the size of the package to take account of participants' differing support needs, and thought a single package amount of \$4,200 did not take into account the range of needs. Many suggested a tiered approach be used similar to CDC, where two or three packages be defined (i.e. low need and high need).

#### *Contingency and surplus funds*

The CDC operational manual requires that individual budgets include a '*small amount to cover contingencies*', which are defined as '*emergency scenarios where needs change*'. Aside from the provider administration charges and the contingency, the manual indicates that '*the remainder of the allocated budget is available to the care recipient to direct to services of their choice.*'

Many CDC and CDRC participants were building up these funds for use in an emergency, for a later period when they knew they may need more support (for example, if they were expecting to be admitted to hospital), or for supports or additional goods or services which were costly and one-off (for example, a holiday for a CDRC participant, or an electric lifting bed for a CDC participant).

A number of participants considered this aspect of the initiative to be particularly important and beneficial, particularly CDRC participants and CDCH and CDCHD participants (where the scope to build up a contingency was greater than for CDCL).

However, providers seemed to differ in their approach to contingencies:

- Providers tended to direct a certain amount of the participant's monthly budget towards a contingency and reflected this in the budget statement. Any other unspent funds for the month would also go towards this surplus or contingency.
- A small number of CDC providers did not allow participants to build up surplus funds. These providers typically budgeted on a month-by-month rather than an annual basis (where participants would have a monthly allocation of hours or funding), and if participants did not utilise their monthly allocation, they would lose any unspent hours or funding.
- Most providers (CDC and CDRC) allowed participants to build up surplus funds, though they were often unclear about the rules around carrying it forward to a subsequent year. As a result, some providers encouraged their participants to spend all of their allocation in the financial year.<sup>14</sup>
- Some providers allowed participants to build up funds and to carry forward any unspent amount to the subsequent financial year.

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<sup>14</sup> The operational manual for CDC allows funds to be carried forward; the CDRC manual is silent on whether funds to be carried forward.

Data was not collected on the size of contingency funds and surpluses accumulated by participants.

**Example**

A CDRC participant was informed that he had \$350 per month available for services and supports (1/12th of a full CDRC package), and that he could not roll over any unspent funds to the following month.

The provider changed their practice and allowed monthly roll-overs following a complaint from the participant, who did not want to spend a set amount each month and did not want to lose a component of his package.

**Key points – Delivery and coordination**

- CDC and CDRC model was characterised by an initial period of intensive assessment and planning involving participants, followed by an ongoing and variable level of support coordination and management once services were in place.
- CDC and CDRC delivery and coordination models involving a progressive increase in consumer control with structured variations in the level of provider care planning and management appeared to be the most transparent and flexible approaches, appealing to a range of consumers across different care levels.
- Separation and clear reporting of provider administration and care planning and management costs in the individual CDC budget appeared to increase transparency and accountability, improve provider efficiency, and enhance the ability for consumers to make informed choices.
- It could be difficult in practice to use CDC and CDRC to engage informal support workers.
- CDC providers did not tend to avail themselves of the opportunity to adjust package allocations. Most providers fixed allocations at the subsidy amount for the care level.
- CDRC providers considered that package funding levels similar to CDC (i.e. low and high) would be useful.

## 5.8 Considerations for special needs groups

Providers suggested that the effectiveness of CDC and CDRC planning, delivery and coordination processes sometimes varied based on the special needs group status of the participant or carer.

*People from Aboriginal or Torres Strait Islander backgrounds*

A number of providers suggested that a different approach may be needed to improve take-up by this group. The CDC/CDRC focus on an individual, rather than the broader family or community, may not be appropriate in the Aboriginal and Torres Strait Islander context.

The potential issues around 'humbugging' also need to be considered ('humbugging' refers to pressure that may be applied by members of a community to an individual seen to be receiving financial benefits, to share those benefits amongst the community).

It is unclear the extent to which Aboriginal and Torres Strait Islander stakeholders were consulted in the development of the initiative and its appropriateness for Aboriginal and Torres Strait Islander people. This would need to be addressed in any wider rollout of CDC.

#### *People living in rural and remote areas*

The key challenge for providers supporting participants in rural and remote areas was being able to offer genuine choice when there may only be one service provider available in a region, and the travel costs involved in engaging an out-of-area provider prohibitive. However, it was suggested that the goals-based approach to planning was particularly helpful for participants and carers in rural and remote areas where there were limited formal services because it encouraged innovative thinking to respond to identified goals and needs.

Another challenge for CDC and CDRC providers was managing their own travel costs and travel time when dealing with participants face-to-face –especially in the up-front initiation and planning stages. For CDRC providers, their challenge was managing these costs within the pre-determined administrative budget for the package. For CDC providers, the challenge was the extent to which they could reasonably pass on travel costs to the participant's package.

#### *People from culturally and linguistically diverse backgrounds*

Planning, coordination and delivery approaches seemed broadly responsive to many of the commonly-cited preferences of culturally and linguistically diverse communities (preferences for gender, language spoken and cultural practices of support workers). A number of CDC and CDRC providers targeting this special needs group already had a large number of clients in this group, and significant experience in meeting the needs of people from culturally and linguistically diverse backgrounds.

#### *People who are homeless or at risk of homelessness*

The key challenge for providers targeting homeless clients was in the initial recruitment. Having identified significant need amongst this group, providers then had to find a way to recruit the actual clients. Most older homeless or itinerant people do not access health services regularly (other than emergency presentations) and there were practical challenges in organising an ACAT assessment or delivering home care services to a person without formal housing.

Providers overcame these challenges by partnering with other organisations, or other sections of their own organisation that provided homelessness outreach services and accommodation. They developed a joint response with the partner provider assisting with recruitment and accommodation, and the CDC provider facilitating the ACAT assessment and then undertaking the CDC planning, delivery and coordination processes. Feedback was that these partnership arrangements were effective, but it did mean that there were delays in operationalising these CDC places because it took time to get the client into stable housing and ACAT assessed. It also took a lot of time to develop the necessary trust between this very independent and sometimes wary client group and the CDC coordinators.

Participants in the homeless special needs group often required a longer, more intensive assessment and planning process, and more intensive case management. They typically had more difficulty identifying their own goals and needs, especially if they have not accessed health or community services in many years, and took more time to feel comfortable engaging in self-direction. They benefited more from a holistic assessment, which included consideration of

other services they might not be accessing, particularly medical care, podiatry, dental care and social support, and they valued the case management – once sufficient trust had been established with the coordinator.

In addition, participants in the homeless special needs group generally showed little interest in the ‘consumer-directed’ aspects of the CDC model, including choice of support and support providers, and their individual budgets.

#### *People who are financially or socially disadvantaged*

There was less direct evidence relating to people in the financially and socially disadvantaged special needs group. This is in many ways a much broader client group than other special needs groups, and it is therefore more difficult to identify particular considerations that can be applied to this group.

#### *Veterans and care leavers*

Only one interviewed provider targeted the Veterans special needs group, though the number of packages allocated to participants in this group was too small to draw any conclusions.

None of the interviewed providers targeted care leavers, and as such there is no information about the applicability of planning, initiation, coordination and delivery processes for these groups.

#### *People living with dementia<sup>15</sup>*

The goals-based process of assessment and planning as described by providers seemed particularly appropriate for people living with dementia and their carers, notably because of the increased focus on the interests, preferences and goals of both the participant and the carer, rather than just a focus on available, pre-determined services. Providers described the steps they took to directly or indirectly include the person living with dementia, and particularly to identify opportunities for social participation and engagement that they might enjoy as part of the holistic planning process.

For this group, it seemed that the planning process (and putting in place appropriately tailored supports in response to that process) was a critical factor in the success of the package. If the planning and initiation process was successful, then the delivery and coordination approaches were also effective. This highlighted the benefit of an initial goal-based planning process.

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<sup>15</sup> People living with dementia are not a designated special needs group under the Aged Care Act.

## 6 Impact of the initiative for CDC participants and their carers

### 6.1 Introduction

This chapter discusses the impact of consumer-directed care for CDC participants and carers. In particular, it addresses two key evaluation questions in relation to CDC:

1. *To what extent was CDC person-centred, and how did it increase choice and control for participants and their carers?* This included satisfaction with the level of control they were able to exercise, choice of services and providers (including support to make informed choices), their freedom to change services or providers, and the satisfaction with CDC.
2. *To what extent did CDC enhance community-based care for participants and their carers?* This included the extent to which CDC helped people achieve their personal goals, the impact of CDC on perceived quality of care, quality of life and general health and wellbeing.

Evidence presented in this chapter is based on information gathered during interviews with CDC participants and their carers, interviews with CDC providers, and a survey of CDC participants and their carers and an equal number of standard packaged care consumers. Detailed data from the participant surveys is provided in Appendix B of this report.

### 6.2 Expectations of participants and carers

#### *Participant and carer motivations for participating in CDC*

A consistent theme from participant and carer interviews was that participants and carers chose to participate in CDC based on the recommendation of their provider, and this is validated through survey data (as the table below illustrates).

A significant number also cited the desire for more choice of services and more control over care planning as reasons for participating in CDC. A desire for more choice of services was a particular motivation for CDCHD participants and their carers.

*Table 10: Reasons for participating in the CDC initiative – by care level*

Reason	CDCL	CDCH	CDCHD
I wanted to have more choice of which services I used	29%	38%	62%
I wanted to have more choice of providers	9%	21%	31%
I wanted to have more control over my care planning	35%	38%	38%
It was recommended by my care provider	72%	82%	38%
I was not satisfied with my previous community care	1%	6%	31%

Based on responses received from 124 CDC participants and 126 standard packaged care (comparison group) recipients. 'Don't know', multiple and blank responses have not been reported in this table. Note that respondents could select more than one reason. Source: CDC and comparison group surveys, conducted August 2011.

There was evidence that prior experience of packaged care influenced participants' motivations for participating in CDC. People who had received a standard care package prior to CDC had a tangible point of comparison – they knew what they wanted to do differently. Some of these people had negative experiences with their prior package or a previous provider, and many were

dissatisfied with some aspects of their package (including some aspect of their support arrangement, their support worker, frustration with a perceived lack of accountability and overly-bureaucratic approaches of some providers). Others were simply attracted to the potential for greater control and/or greater accountability offered by CDC, and saw CDC as a means of having a greater say over their supports and influence over how their supports were to be provided.

Survey data revealed some differences in reasons for participating in CDC between participants who had prior experience of packaged care and those that had not. Both groups identified recommendations by their care provider as the most common reason for participating in CDC, though a higher proportion of participants who had received packaged care before identified having more choice of services and more control over care planning as important, compared with participants who had not received packaged care before. This is illustrated in the table below.

*Table 11: Reasons for participating in the CDC initiative – by package care history*

Reason	Received packaged care before	Had not received packaged care before
I wanted to have more choice of which services I used	41%	30%
I wanted to have more choice of providers	16%	18%
I wanted to have more control over my care planning	46%	34%
It was recommended by my care provider	70%	75%
I was not satisfied with my previous community care	11%	2%

Based on responses received from 124 CDC participants and 126 standard packaged care (comparison group) recipients. 'Don't know', multiple and blank responses have not been reported in this table.

Source: CDC and comparison group surveys, conducted August 2011.

### *Carer perspectives*

For many carers, the perceived recognition of their central role in the participant's care and the capacity to have their views and preferences considered in the care planning process were key factors in their decision to participate in CDC.

It is important to bear in mind that where there was a carer actively involved, participants and carers often made decisions as a unit. They recognised that the funded care and services were primarily for the participant's direct benefit, but they saw the package as a source of support for both the participant and carer, and one of their key expectations of CDC was that carers and participants were jointly involved in planning and decision-making. Where the participant's capacity was limited (due to dementia, for example), then the carer took the lead role though considering both their own needs and the needs of the participant (the person they cared for).

#### Key points – Participant and carer motivations for participating in CDC

- Participants and carers primarily chose CDC on the recommendation of their service provider. A number of participants also indicated a desire for more choice of supports, and more control over the supports they received.
- Participants and carers with prior experience of community care had clearer expectations of CDC. Some expressed frustration and dissatisfaction with aspects of their previous care arrangements, and wanted a greater say over their care and influence over how their care is provided.
- Carers of CDCH and CDCHD participants were particularly attracted to CDC because of the scope for them to exercise more control and involvement in decision-making, and were attracted to the increased budget transparency that CDC provided.

### 6.3 Extent to which CDC was person-centred and increased choice and control

The extent to which CDC was person-centred and increased participants' choice and control encompassed the following aspects:

- participants' involvement in planning and decision-making
- extent of participant choice of supports and support providers
- participants' ability to make informed choices
- extent of participant control over the supports they received.

#### *Involvement in planning and decision-making*

##### *Nature of involvement in care planning and budget planning processes*

As described in chapter 3, most participants were involved in a series of face-to-face discussions with a coordinator to determine their level of interest in CDC and their capacity to be involved in CDC. They also discussed their needs, and in some cases what they wanted to achieve from their package.

There were a range of views expressed by participants about their involvement in planning and decision-making. Participants who had been on a standard package were relatively uninterested in the planning aspects of CDC, particularly if they were satisfied with their current support arrangements or wanted to make only minor changes, and particularly if they had transferred from a CACP to a CDCL package. For this group, planning was rarely 'from scratch', and generally not goal-based. The majority of new CDCL participants were focussed on the supports that they could access – similar to new standard package recipients.

A number of participants commented that they relied on their coordinator to make suggestions and provide options relating to different types of supports and support arrangements. Decisions about which supports they needed, their support providers, and support arrangements (such as days and times a support worker would come to their home) were generally made with assistance or advice from the CDC coordinator. The relationship with their coordinator was considered to be important by many participants and carers.

CDCH and CDCHD participants, and specifically their carers, appeared to be more actively involved in planning and decision-making, and some participants and carers (usually younger carers) with prior experience of community care had clear ideas about what they wanted in terms of supports. This was driven to some extent by dissatisfaction with their previous package.

Once the supports were in place, the level of contact with the CDC coordinator would taper off to regular 'check ins' and monitoring, usually by phone rather than face-to-face. The extent to which this did happen varied: some participants and older carers indicated a relatively high level of ongoing contact with and coordination by the CDC provider.

*"(The coordinator) is really committed and wants to help me keep Mum at home and care for her the way I want her cared for. (The coordinator) has gone the extra mile – she found about all these other services, things like music therapy and massage, and suggested we could try some of those as part of the package, to help manage Mum's behaviour."*

Carer of CDCHD participant  
aged in her 50s

#### *Level of satisfaction with involvement in care planning and budgeting*

The majority of CDC participants and carers were satisfied or very satisfied with their level of involvement in planning and decision-making, and the majority of participants felt their needs were taken into account. However, there was a degree of dissatisfaction with some providers, and in particular relating to their perceived inflexibility regarding what a package could be used for.

Overall, the survey showed that 91 per cent of CDC participants and carers agreed or strongly agreed that they felt included in the care planning and decision-making process. Interestingly, only a slightly lower proportion of people in the comparison group (86 per cent) also agreed or strongly agreed that they felt included in the care planning process (table B.6 in Appendix B refers).

Similarly, 95 per cent of CDC participants and carers agreed or strongly agreed that their needs and goals were taken into account during the care planning process. A similar proportion of people in the comparison group (92 per cent) also agreed or strongly agreed that their needs and goals were taken into account (table B.7 in Appendix B refers).

There were some differences between care levels, as illustrated in the tables below. The tables show that:

- The level of agreement with the statement *'I felt included in the process of planning my care services'* was broadly similar for CDCL and CACP comparison group respondents. However, a higher proportion of CDCH participants agreed with the statement compared with the EACH comparison group.
- A much greater proportion of CDCH participants (53 per cent) strongly agreed with the statement *'my needs and goals were taken into account in the planning of my care and services'* compared with EACH comparison group respondents (14 per cent). This was not the case for CDCL participants.

*Table 12: I felt included in the process of planning my care services*

	CDCL	CACP	CDCH	EACH
Strongly disagree	0%	0%	0%	3%
Disagree	1%	0%	0%	0%
Neither agree nor disagree	4%	4%	0%	7%
Agree	56%	55%	53%	62%
Strongly agree	35%	39%	47%	21%

Based on responses received from 124 CDC participants and 126 standard packaged care (comparison group) recipients. 'Don't know', multiple and blank responses have not been reported in this table.

Note that there were insufficient responses CDCHD and EACHD recipients to be included in the analysis

Source: CDC and comparison group surveys, conducted August 2011.

*Table 13: My needs and goals were taken into account in the planning of my care and services*

	CDCL	CACP	CDCH	EACH
Strongly disagree	0%	0%	0%	0%
Disagree	1%	0%	0%	3%
Neither agree nor disagree	1%	1%	0%	3%
Agree	60%	51%	47%	76%
Strongly agree	35%	45%	53%	14%

Based on responses received from 124 CDC participants and 126 standard packaged care (comparison group) recipients. 'Don't know', multiple and blank responses have not been reported in this table.

Note that there were insufficient responses CDCHD and EACHD recipients to be included in the analysis

Source: CDC and comparison group surveys, conducted August 2011.

Respondents with no prior experience of packaged care had a slightly higher level of satisfaction with the degree to which they felt included in the planning process, and the degree to which their needs and goals were taken into account, compared with those who had transferred to CDC from a standard care package (tables B59-60 in Appendix B refer).

### *Budgeting*

There were varying levels of interest in the budgeting aspects of CDC. Generally, CDCL participants did not express a high level of interest in the budget planning or ongoing budget monitoring (including monthly statements), other than knowing whether their package was over or under-spent, and participants often left the budgeting aspects of planning to their coordinator.

CDCH participants and carers of CDCH and CDCHD participants expressed more interest in budget planning and monitoring, and in the costs of supports. A number of people indicated that the transparency of the budgeting and transparency of support costs was an important aspect of CDC: it provided them with important information to use in choosing supports and support providers, to plan for future events (and build up contingencies), and to some extent

gave them reassurance that the person they cared for was receiving full value from the package.<sup>16</sup>

Many participants and carers were interested in the capacity to accrue contingency funding or surplus funding (though the extent to which this was permitted depended on individual provider approaches). Having the capacity to accrue contingency funding was identified as an important aspect of the CDC model because it allowed participants and carers to more effectively plan for the future and provided important reassurance to participants and carers that they had funds available should their needs or circumstances change. There was a greater level of interest among CDCH and CDCHD participants and carers, where the scope to accumulate contingency or surplus funding was greater than for CDCL, though some CDCL participants also highlighted the benefit of building up a contingency fund.

*"I should have full control of the budget. Yes, there need to be safeguards. You could park the funds with an independent financial intermediary (not an aged care provider). You could be supervised for a period until you're shown to be competent. After that, you should be able to run it all yourself and use the administration funds to buy more care hours."*

Carer of CDCH participant  
aged in her 40s

A small number of participants interviewed were unsure about whether they had been provided with a breakdown of how their package had been allocated, and some indicated that they had not seen any regular budget statements outlining how their package had been spent and the funding left to spend.

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<sup>16</sup> There was, however, a level of dissatisfaction among a small number of participants and carers about the lack of information and justification of the case management and administration fees applied by providers. These participants and carers generally felt these costs were too high and could not understand how they compared to a standard package.

### Key points – Involvement in planning and decision-making

- The majority of CDC participants and carers were satisfied or very satisfied with their level of involvement in planning and decision-making, though there was little difference between CDC participants and standard packaged care recipients.
- CDCH and CDCHD participants and their carers appeared to be more interested and actively involved in planning and decision-making than CDCL participants. Participants and carers (usually younger carers) with prior experience of community care generally had clear ideas about what they wanted in terms of supports.
- Participants and carers valued the individualised, face-to-face planning process with a consistent, single coordinator or case worker.
- There was inconsistency in the provision of documented care plans and individual budget statements to participants.
- The capacity to build up contingency or surplus funding was considered an important aspect of the CDC model, and is an important component of planning.
- Clients' level of interest in the individual budget varied depended in the care level (CDCL participants were less interested than CDCH and CDCHD), and the age of the carer (younger carers particularly valued the transparency and accountability of the individual budget).
- Participants and carers generally felt they had enough information to make informed choices.

### Extent of participant 'choice'

The interviews suggested that the majority of CDC participants and carers were satisfied with their level of choice and options in relation to supports, though there were some participants who did express dissatisfaction.

For the most part, the supports people chose were similar to those available under standard packaged care and largely focussed on core services. The extent to which they were offered real choice by providers depended on the provider's approach to planning, the extent to which they provided information on what supports were available and from whom, and the cost of those supports. There was some evidence of a degree of participant and carer dissatisfaction and frustration with the choices they had – particularly when they requested (and were denied) services which were not consistent with the 'usual menu' of community aged care supports.

*"Don't get me wrong, CDC is better than EACHD, but it does not really give you choice or control. It's still inflexible and bureaucratic. I want to use some of the funds for things like help with ironing, or taking Dad to the club now and then – which he would really love – but the answer is always 'no'. Why shouldn't we be able to do those things?"*

Carer of CDCHD participant

Several CDC providers had concerns about balancing the consumer choice element of CDC with the provider's duty of care. Several providers gave examples of requests by participants or carers for use of CDC funds that they had refused, primarily because they considered that the request was not an appropriate use of funds or because the request would compromise the

participant's care (for example, reducing the amount of personal care or clinical care a participant could use). Other providers were also concerned by participants choosing to build up a sizeable contingency fund by foregoing some regular supports. While providers discussed and negotiated alternatives, this highlighted one of the key tensions in the CDC model.

There were some examples of creative and innovative uses of package funds, though perhaps not to the same extent as for CDRC.

#### **Examples of innovative or non-traditional uses of CDC package funds**

A CDC participant with mobility limitations purchased a shower stool and arranged for bathroom modifications to enable her to shower herself independently rather than rely on daily personal care. The CDC funds saved were put towards fresh food purchases to help improve her general health.

A CDCL participant used his package to purchase a light-weight vacuum cleaner so he could clean his flat himself, rather than using his package for domestic assistance.

A CDCL participant who was formerly homeless had a goal to improve his overall health, and he used his package for a variety of dental and podiatry services. He also used some of his CDC funds to attend a country music festival.

A CDCHD participant from a CALD background wanted to spend time with others that spoke his language. His CDC provider found a centre-based day service for people who spoke his native language and he used her package to attend this once a week. This option was identified after his family's first preference – to have a personal support worker who spoke the participant's language – was unable to be met due to a lack of workers with the language skills needed.

The proportion of CDC participants who were satisfied with the range of services that they could choose was not considerably different from the standard packaged care comparison group (table B.43 in Appendix B refers). In fact, the level of satisfaction of the CDC group was slightly lower than the comparison group.

Similarly, there were no clear conclusions about levels of satisfaction with the range of services participants could choose – either between CDC participants on different package levels, or between CDC participants with previous packaged care experience and those who were new to packaged care (Table B.61 refers).

#### ***Ability of participants to make informed choices***

The majority of participants and carers interviewed considered that they had enough information to make decisions – although a number of generally older participants and carers suggested that there was too much information for them to process.

One area where participants wanted more information related to the restrictions and limitations placed on the use of their package. Some participants and carers were frustrated when their provider refused requests for specific supports, services or goods – generally those which were not 'traditional' supports funded through standard packages<sup>17</sup> – particularly where there was

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<sup>17</sup> Examples included computers and internet connections, engagement of informal workers (such as family members), requests for cash payments of CDC funds, or requests to use CDC funds on informal social activities), and those requests were denied.

insufficient information about why the requests were inappropriate. It was clear during the provider interviews that providers took very different approaches to the same kinds of requests – with some providers more open to specific services or goods that other providers would refuse to consider.

The survey results suggest that most participants and carers felt they had enough information overall to make informed choices. However, it should be noted that 12 per cent of participants and carers disagreed or strongly disagreed that they had enough information about *types* of services available, or the *costs* of services. This was also reflected in the interviews.

### ***Extent of participant ‘control’***

There was evidence that participants and carers exercised a level of control over how supports were provided, including the hours of care, service times, service frequency, access to services and care in the evening and weekends, and tailoring of supports around participant and carer preferences and schedules. In addition, a number of participants stated that they were able to choose their support workers and to trial a few support workers until they found one they liked.

Participants indicated that having this control and flexibility was the key benefit of CDC, and for those with prior community care experience, this was the key differentiator of the CDC approach from standard packaged care. However, there was also a degree of dissatisfaction with some CDC providers who were not flexible and responsive to participants’ preferences and requests. Again, the degree of control and input a participant had regarding their supports differed across providers, either because of inflexibility on the part of the provider, or a lack of understanding or awareness on the part of the participant that they could have this control or influence.

A number of participants and carers with prior experience of community care said that they felt much more empowered to ask for changes to their support arrangements under the CDC model, such as a change in support worker. Some of these participants and carers indicated that, under standard packaged care, they had felt fearful of asking for changes or making complaints because they were worried their services would be withdrawn.

*“They were very good about giving you information on which providers you could use and how much they cost. I felt like I had enough to go on, but to be honest I was never sure how much choice there really was. I just went with the options that allowed me to get the most out of the package.”*

CDCL participant  
aged in her 70s

There were some minor differences in level of agreement with the survey question *“I feel like I have control the care and services I receive”* between CDC participants and the comparison group, and between CDCL and CDCH:

- lower levels of agreement among CDCL respondents compared with CACP respondents
- higher levels of agreement among CDCH respondents compared with EACH respondents, and higher levels of agreement among CDCH respondents compared with CDCL
- higher levels of agreement among CDC respondents with no packaged care history compared with those with previous packaged care experience

These points are illustrated in the tables below.

*Table 14: I feel like I have control the care and services I receive*

	CDCL	CACP	CDCH	EACH
Strongly disagree	0%	0%	0%	0%
Disagree	4%	0%	3%	0%
Neither agree nor disagree	7%	4%	3%	10%
Agree	65%	55%	50%	69%
Strongly agree	18%	36%	44%	17%

Based on responses received from 124 CDC participants and 126 standard packaged care (comparison group) recipients. 'Don't know', multiple and blank responses have not been reported in this table.

Note that there were insufficient responses CDCHD and EACHD recipients to be included in the analysis

Source: CDC and comparison group surveys, conducted August 2011.

*Table 15: I feel like I have control the care and services I receive*

	Receive packaged care before	Did not receive packaged care before
Strongly disagree	0%	0%
Disagree	5%	4%
Neither agree nor disagree	3%	0%
Agree	66%	60%
Strongly agree	19%	33%

Based on responses received from 124 CDC participants and 126 standard packaged care (comparison group) recipients. 'Don't know', multiple and blank responses have not been reported in this table.

Source: CDC and comparison group surveys, conducted August 2011.

Interestingly, the responses to the survey question "Compared to six months ago, how satisfied were you with the level of control that you feel you have over your care?" illustrates a different picture – with CDC respondents (both CDCL and CDCH) reporting a greater level of satisfaction than the standard packaged care group.

*Table 16: Compared to six months ago, how satisfied were you with the level of control that you feel you have over your care?*

	CDCL	CACP	CDCH	EACH
Not satisfied	1%	0%	0%	0%
Somewhat less satisfied	4%	1%	0%	7%
No different	22%	44%	15%	62%
Somewhat more satisfied	29%	29%	35%	24%
Much more satisfied	35%	23%	41%	3%

Based on responses received from 124 CDC participants and 126 standard packaged care (comparison group) recipients. 'Don't know', multiple and blank responses have not been reported in this table.

Note that there were insufficient responses CDCHD and EACHD recipients to be included in the analysis.

Source: CDC and comparison group surveys, conducted August 2011.

### *Degree to which participants and carers were able to self-manage*

Most participants were able to manage their package to some degree, at least to the level of making simple, day-to-day bookings and scheduling changes, maintaining timesheets, and managing problems such as support workers being late. However, few participants took on a substantial self-management role – either because they were not given that option by their provider, had no interest in self-managing their package and their support arrangements, or did not feel that they were able to.

Some participants and carers interviewed described how their CDC provider worked with them to understand their package, and to build their capacity to monitor and manage aspects of their package and their support arrangements themselves. This included providers explaining to them how to interpret budget statements, use timesheets, deal with service providers, and resolve problems with their support themselves (such as what to do if a support worker did not show up, or there were concerns about quality of the support).

Younger carers of CDCH and CDCHD participants were generally able and more willing to predominantly self-manage their package, often with very little or no assistance from their CDC provider. There were also some older participants and carers who showed an interest in self-management. Some carers were particularly concerned that they did not have enough control of their package and in particular enough control of the package funds.

#### Key points – Person-centredness, choice and control

##### *Choice and control*

- The majority of CDC participants were satisfied with their level of choice and control. CDCL participants were less satisfied than CDCH and CDCHD on all measures.
- For the most part, people chose the same *types* of services as those available under standard packaged care, and they exercised choice and control over *how* the services were delivered (mostly around flexible service delivery and continuity of support workers).
- Provider attitudes to requests for services or other supports that were inconsistent with the ‘usual menu’ of services, or were different from the usual way services were provided, varied considerably. This reflects the differing positions of providers in terms of their person-centredness (as discussed in the previous chapter). This meant that some CDC participants had less choice and control over their supports than other participants.
- Some carers (generally younger carers) wanted more control over the budget and more scope to use funds for ‘non-traditional’ purposes.
- The extent to which participants and carers self-managed their package depended on their level of interest, effectiveness of provider capability building/mentoring for them, simplicity of the paperwork they needed to complete, and the extent to which they needed or wanted support to coordinate and manage their package from their provider. It also depended on the extent to which their package provider ‘allowed’ them to self-manage, which in part was related to the provider’s perception of risk and the provider’s degree of risk aversion.
- Younger carers of CDCH and CDCHD participants were able to self-manage to a greater extent than others.

## 6.4 Extent to which CDC enhanced community-based care

In considering the extent to which CDC enhanced community-based care, the evaluation focused on the impact of CDC on participant and carer perceptions of:

- quality of care
- their ability to achieve personal goals
- their quality of life, health and wellbeing.

### ***Impact on quality of care***

Overall, CDC participants and carers were slightly more satisfied with the quality of care they received than standard packaged care recipients. A number of CDCH and CDCHD participants and carers in particular, and those participants with prior experience of packaged care felt that their quality of care had improved. This was mainly due to them being able to have more control over when and how the care and services were delivered, such as choosing their support worker, being able to structure their support around their preferences and schedules, receiving support at night and over the weekend, and to a lesser extent the greater choice of providers.

*“All I want is for my father to be cared for the way I would care for him. That is what (CDC) has given me, and I am very happy with it.”*

Carer of CDCH participant

Survey responses to the question *“I am satisfied with the quality of care and services I receive”* showed high levels of satisfaction in both the CDC participant group and the packaged care comparison group. However, there was little difference between the two (table B.19 in Appendix B refers). There were also no clear differences between those participants with prior experience of packaged care and those that had not (table B.64 in Appendix B refers). Consistent with the interview findings, CDCH participants were slightly more satisfied with the quality of their care than CDCL participants (table B.46 in Appendix B refers).

### ***Achieving personal goals***

While a number of providers used a goal-based approach to planning, participants did not talk about their ‘personal goals’ as such. They tended to focus on the hours of care they received, the range of services they could access and how they hoped these would help them remain at home and, especially for CDCL participants, remain independent.

Carers were more likely to articulate particular goals, and these often focussed around their desire for more flexible service delivery to fit around their lives so they could continue working (in the case of younger carers) or spend more time doing other things that were important to them, while knowing that the care recipient would be well cared for.

CDC participants and carers were more satisfied with their ability to achieve their personal goals than packaged care recipients. There was a higher level of favourable response to the survey question *“Compared to six months ago, how satisfied are you with your ability to achieve the things you want to achieve?”* for CDCL participants (compared with CACP recipients), and CDCH participants (compared with EACH recipients). Consistent with most of the other survey questions, the level of satisfaction was higher for CDCH participants compared with CDCL.

Among the CDC participant group, there was a noticeably higher level of satisfaction with their ability to achieve their goals among those with prior experience of package care compared with those that had not.

*Table 17: Compared to six months ago, how satisfied were you with your ability to achieve the things you want to achieve? – by care level*

	CDCL	CACP	CDCH	EACH
Not satisfied	3%	3%	3%	3%
Somewhat less satisfied	4%	6%	9%	10%
No different	28%	39%	21%	45%
Somewhat more satisfied	31%	23%	24%	24%
Much more satisfied	28%	26%	38%	14%

Based on responses received from 124 CDC participants and 126 standard packaged care (comparison group) recipients. 'Don't know', multiple and blank responses have not been reported in this table.

Note that there were insufficient responses CDCHD and EACHD recipients to be included in the analysis

Source: CDC and comparison group surveys, conducted August 2011.

*Table 18: Compared to six months ago, how satisfied were you with your ability to achieve the things you want to achieve? – by package care history*

	Receive packaged care before	Did not receive packaged care before
Not satisfied	0%	7%
Somewhat less satisfied	3%	7%
No different	22%	27%
Somewhat more satisfied	32%	27%
Much more satisfied	36%	27%

Based on responses received from 124 CDC participants and 126 standard packaged care (comparison group) recipients. 'Don't know', multiple and blank responses have not been reported in this table.

Source: CDC and comparison group surveys, conducted August 2011.

### ***Impact on quality of life, health and wellbeing***

Even after a short period of operation, and considering the differences in implementation of CDC by providers (and the extent to which CDC is different from standard packaged care), CDC appeared to have an impact on participants' satisfaction with various aspects of their life.

This included their ability to participate in social and community activities, their ability to visit family and friends, the quality of their home life and close relationships, and their health and wellbeing. For all of these aspects, satisfaction was higher for CDCH participants than for CDCL, and higher than standard package care recipients.<sup>18</sup> CDC participants who had prior experience of packaged care tended to have higher levels of satisfaction with some of these aspects than those participants with no prior experience of packaged care. To a large extent, the flexibility of supports and the level of control and input that participants had over their supports were key contributors to these outcomes.

While there were noticeable differences, they are not substantial, and this may reflect the length of time that participants had experience of CDC. Further, on the single measure of wellbeing,

<sup>18</sup> The number of responses for CDCHD and EACHD recipients was low, hence have not been reported.

there was no statistically significant difference between the CDC participant group and the standard packaged care comparison group.

Different aspects of participants' quality of life, health and wellbeing are discussed below.

### Independence

A number of participants and carers spoke about feeling more able to do the things they wanted to do because of the flexibility of their supports. This was particularly apparent for carers of CDCH and CDCHD participants, many of whom stated that they felt more independent and able to do things they wanted to do (as carers), and less burdened with their caring role.

A greater proportion of CDC survey respondents indicated that they were more satisfied with the level of independence compared with six months ago than the packaged care comparison group. In particular, CDCH participants had a considerably higher level of satisfaction with their level of independence compared with EACH recipients. This is illustrated in the table below.

*A CDCH participant, aged in his 60s, living in a regional town needed personal care assistance in the evenings, and assistance to transfer from his wheelchair to bed. He occasionally attended music concerts in the evening. Through his CDC provider he arranged for supports to be provided later than normal on the nights he attended a concert – often after 10pm. Without this late night support, he would not be able to attend the concerts – an activity which he enjoyed.*

There were no clear differences between those participants with prior experience of packaged care and those that had not, however (table B.75 refers).

*Table 19: Compared to six months ago, how satisfied were you with your level of independence?*

	CDCL	CACP	CDCH	EACH
Not satisfied	6%	3%	3%	7%
Somewhat less satisfied	10%	11%	15%	21%
No different	41%	55%	29%	62%
Somewhat more satisfied	19%	16%	32%	3%
Much more satisfied	19%	13%	18%	7%

Based on responses received from 124 CDC participants and 126 standard packaged care (comparison group) recipients. 'Don't know', multiple and blank responses have not been reported in this table.

Note that there were insufficient responses CDCHD and EACHD recipients to be included in the analysis.

Source: CDC and comparison group surveys, conducted August 2011.

### Participation in social and community activities

A higher proportion of CDC survey respondents indicated that they were more satisfied with their ability to participate in social and community activities than the packaged care group, and this was also reflected in the CDCL group (higher than the CACP group), and the CDCH group (higher than EACH). This is highlighted in the table below.

Many participants identified the flexibility of supports as a key enabler – allowing them to structure their supports around their own and their carer’s schedules, and being able to utilise supports (such as transport) to directly facilitate access to social and community events and activities for themselves and/or their carers.

*Table 20: Compared to six months ago, how satisfied were you with your ability to participate in social and community activities?*

	CDCL	CACP	CDCH	EACH
Not satisfied	3%	1%	3%	3%
Somewhat less satisfied	3%	10%	6%	17%
No different	40%	41%	32%	55%
Somewhat more satisfied	31%	26%	26%	14%
Much more satisfied	18%	16%	24%	3%

Based on responses received from 124 CDC participants and 126 standard packaged care (comparison group) recipients. ‘Don’t know’, multiple and blank responses have not been reported in this table.

Note that there were insufficient responses CDCHD and EACHD recipients to be included in the analysis.

Source: CDC and comparison group surveys, conducted August 2011.

There were no noticeable differences between those participants with prior experience of packaged care and those that had not, however (table B.70 in Appendix B refers).

### *Relationships*

There were higher levels of satisfaction among the CDC respondent group with their ability to visit family and friends and their satisfaction with the quality of their home life and close relationships, compared with the packaged care comparison group. CDCH participants were noticeable more satisfied than EACH package recipients, and more satisfied than CDCL participants. This is illustrated in the tables below.

*Table 21: Compared to six months ago, how satisfied are you with the extent which you are able to visit your family and friends?*

	CDCL	CACP	CDCH	EACH
Not satisfied	3%	1%	3%	10%
Somewhat less satisfied	3%	9%	9%	7%
No different	56%	68%	29%	69%
Somewhat more satisfied	26%	8%	35%	7%
Much more satisfied	7%	11%	21%	3%

Based on responses received from 124 CDC participants and 126 standard packaged care (comparison group) recipients. ‘Don’t know’, multiple and blank responses have not been reported in this table.

Note that there were insufficient responses CDCHD and EACHD recipients to be included in the analysis.

Source: CDC and comparison group surveys, conducted August 2011.

*Table 22: Compared to six months ago, how satisfied are you with the quality of your home life and close relationships?*

	CDCL	CACP	CDCH	EACH
Not satisfied	3%	0%	0%	3%
Somewhat less satisfied	1%	5%	3%	7%
No different	46%	59%	50%	69%
Somewhat more satisfied	25%	18%	18%	14%
Much more satisfied	19%	16%	29%	7%

Based on responses received from 124 CDC participants and 126 standard packaged care (comparison group) recipients. 'Don't know', multiple and blank responses have not been reported in this table.

Note that there were insufficient responses CDCHD and EACHD recipients to be included in the analysis.

Source: CDC and comparison group surveys, conducted August 2011.

As illustrated in the following tables, there were also higher levels of satisfaction with participants' home life and close relationships and ability to visit family and friends among the CDC group who had prior experience of package care compared with those that had not.

*Table 23: Compared to six months ago, how satisfied are you with the extent which you are able to visit your family and friends?*

	Received packaged care before	Did not received packaged care before
Not satisfied	0%	7%
Somewhat less satisfied	3%	7%
No different	47%	56%
Somewhat more satisfied	32%	16%
Much more satisfied	12%	13%

Based on responses received from 124 CDC participants and 126 standard packaged care (comparison group) recipients. 'Don't know', multiple and blank responses have not been reported in this table.

Source: CDC and comparison group surveys, conducted August 2011.

*Table 24: Compared to six months ago, how satisfied are you with the quality of your home life and close relationships?*

	Received packaged care before	Did not received packaged care before
Not satisfied	0%	4%
Somewhat less satisfied	2%	2%
No different	41%	53%
Somewhat more satisfied	29%	20%
Much more satisfied	22%	20%

Based on responses received from 124 CDC participants and 126 standard packaged care (comparison group) recipients. 'Don't know', multiple and blank responses have not been reported in this table.

Source: CDC and comparison group surveys, conducted August 2011.

## Health and wellbeing

There was also some evidence that CDC was having a positive impact on CDC participants' health and wellbeing. While some participants interviewed stated that their physical health had improved since being on CDC (mainly due to direct access to health-related supports), a number of participants and their carers identified an improved sense of 'wellbeing' and a different outlook or perspective on life – predominantly due to feeling more in control of their care (and their lives). Survey responses also indicated a greater level of satisfaction among CDCH participants compared with EACH package recipients – as illustrated in the table below.

*"After my wife died, I didn't really care what happened to me. Now, I am starting to care a bit, and even think about the future. (The CDC coordinator and support workers) have helped me start thinking about the future."*

CDCL participant, formerly homeless  
aged in his 60s

**Table 25: Compared to six months ago, how satisfied were you with your general health and wellbeing?**

	CDCL	CACP	CDCH	EACH
Not satisfied	7%	4%	3%	14%
Somewhat less satisfied	15%	23%	15%	14%
No different	26%	30%	35%	52%
Somewhat more satisfied	35%	25%	21%	14%
Much more satisfied	15%	16%	26%	7%

Based on responses received from 124 CDC participants and 126 standard packaged care (comparison group) recipients. 'Don't know', multiple and blank responses have not been reported in this table.

Note that there were insufficient responses CDCHD and EACHD recipients to be included in the analysis.

Source: CDC and comparison group surveys, conducted August 2011.

There were also higher levels of satisfaction with general health and wellbeing for CDC participants who had received packaged care before commencing a CDC package compared with those with no packaged care history – as indicated in the table below.

**Table 26: Compared to six months ago, how satisfied are you with your general health and wellbeing?**

	Received packaged care before	Did not receive packaged care before
Not satisfied	2%	11%
Somewhat less satisfied	14%	18%
No different	27%	33%
Somewhat more satisfied	39%	18%
Much more satisfied	17%	20%

Based on responses received from 124 CDC participants and 126 standard packaged care (comparison group) recipients. 'Don't know', multiple and blank responses have not been reported in this table.

Source: CDC and comparison group surveys, conducted August 2011.

### Measure of wellbeing

The CDC and packaged care comparison group surveys included a partial measure of outcome – the ICECAP-O<sup>19</sup> wellbeing measure.

The median ICECAP-O scores for the CDC and packaged care comparison group are outlined in the table below. As the table shows, there were only very slight differences between the median scores for CDCL and CDCH participants compared with the CACP and EACH comparison groups, and for the CDC participant group overall.<sup>20</sup> Differences were not statistically significant.<sup>21</sup>

Table 27: ICECAP-O wellbeing measures – median scores

Response	CDC	Comparison
CDCL/CACP	0.85	0.84
CDCH/EACH	0.70	0.63
CDCHD/EACHD	...	...
<b>Median score</b>	<b>0.77</b>	<b>0.79</b>

A score of 1 is the maximum wellbeing score, and a score of 0 the minimum.

Based on responses received from 124 CDC participants and 126 standard packaged care (comparison group) recipients. Note that respondents who did not complete all five items have been excluded.

Source: CDC and comparison group surveys, conducted August 2011.

<sup>19</sup> The 'ICEpop CAPability measure for Older people' (ICECAP-O) is a validated measure of wellbeing in older people. The ICECAP-O tool uses a definition of wellbeing which is broader than most other measurement tools (which focus on health and/or functional capability), and covers five attributes of wellbeing that were found to be important to older people in the UK: *Attachment* (love and friendship), *Security* (thinking about the future without concern), *Role* (doing things that make you feel valued), *Enjoyment* (enjoyment and pleasure), *Control* (independence). The ICECAP-O tool provides a single wellbeing score (between 0 and 1) for each individual completing the five-question tool.

Source: <http://www.icecap.bham.ac.uk/ICECAP-O/index.shtml>, accessed September 2011.

<sup>20</sup> Data is not able to be reported separately for CDCHD and EACHD given the low number of respondents, though they have been included in the overall median scores for CDC and comparison groups.

<sup>21</sup> using the Mann-Whitney test for non-normally distributed data, p=0.05

#### Key points – Enhancing community-based care

- Even after a short period of operation, CDC appeared to have a positive impact on participants' level of satisfaction with various aspects of their life - including their ability to participate in social and community activities, their ability to visit family and friends, the quality of their home life and close relationships, and their health and wellbeing.
- Satisfaction was generally higher for CDCH participants than for CDCL, indicating that there is potentially more benefit for people with higher levels of need (and receiving more sizeable packages). Key enablers to these higher levels of satisfaction are the degree of flexibility and control participants have over their support arrangements.
- Satisfaction was also generally higher for CDC participants who had prior experience of packaged care compared with those participants with no prior experience of packaged care, indicating that CDC represents an improvement over standard packaged care for many participants.
- While there are noticeable differences, they are not substantial, and this may reflect the length of time that participants had experience of CDC. Further, on the single measure of wellbeing, there was no statistically significant difference between the CDC participant group and the standard packaged care comparison group.

## 6.5 Impacts on carers

### *Role and involvement of carers in CDC*

Most CDCH participants, and all CDCHD participants, had one or several carers (their 'nominated representative', and sometimes other family members or friends) who were actively involved in all stages of their CDC package, including:

- making the initial decision to participate in CDC
- care planning and budgeting process
- monitoring of service delivery
- liaising with the CDC provider and agencies/service providers
- undertaking the day-to-day coordination of the package.

Carers were typically spouses or adult children (often daughters) of the CDC participant, but there was a wide range of caring relationships including children-in-law, nieces and nephews, and friends. It was clear that carers played a key role in decision-making in high care CDC packages. Decisions tended to be made either jointly between the carer(s) and participant, or,

*"I strongly believe the carer and the family must be involved planning the specific supports needed – you should not just be given a list of services to pick from and a bit of choice about who will deliver them. In my experience, most aged care providers struggle to understand this approach. CDC is better, but it's still not what I would call person- or family-centred."*

Carer of CDCH participant  
aged in her 40s

depending on the participant's frailty, dementia status and/or level of engagement and interest, by the carer(s).

The role of carers in CDCL packages was less prominent. Several CDCL participants interviewed for the evaluation saw the package as a way for them to maintain their independence and to minimise reliance on family members. Where CDCL participants did have carers, the carers also expected to play an active part and have their role as a carer respected by the CDC provider.

Overall, the interlinked roles of participant, carers and families in the CDC process meant that it was sometimes difficult to distinguish the views of the participant and the carer(s) in the surveys and interviews because they saw themselves as a unit and the CDC package as a family support.

## 6.6 Considerations for special needs groups

There were a number of issues identified specific to special needs groups.

### *People from Aboriginal or Torres Strait Islander backgrounds*

About 3 per cent of CDC participants identified as being of Aboriginal or Torres Strait Islander origin. Providers indicated that there was a lower than hoped for take-up of CDC by Aboriginal and Torres Strait Islander clients, suggesting that the CDC approach may not be cultural appropriate in its current form, and that modifications to the approach may be warranted for Aboriginal and Torres Strait Islander participants (for example, including the broader family or community in the planning process, or planning at a community level rather than an individual level).

One issue that was a concern for some Aboriginal and Torres Strait Islander participants (and providers targeting the Aboriginal and Torres Strait Islander special needs group) was 'humbugging'. For some clients, the CDC individual budget statements were useful for managing this, because they could show people where all of the funds were being expended. Other participants, however, thought the budget statements added to the problem. The number of participants represented in the evaluation data collections was too small to form any firm conclusions; however this concern should be examined further.

### *People living in rural and remote areas*

CDC participants and carers living in rural and remote areas indicated similar levels of satisfaction as any other group with the CDC planning process, choice of services, level of control and quality of care. This was interesting, because in many cases there was less choice of service providers and/or increased costs involved in using services (because of the transport costs involved in engaging out-of-area providers).

### *People from culturally and linguistically diverse backgrounds*

Culturally and linguistically diverse clients indicated similar levels of satisfaction with the CDC planning process, choice of services, level of control and quality of care as any other group. Of particular importance to these clients was having the ability for services to be delivered by workers who spoke the same language as the care recipient. For a number of people, this was their key requirement of CDC.

Outside of major cities, it was not always possible to broker support workers with the required language skills (and even in major cities it could be challenging to ensure that all support workers have the necessary care skills and language skills).

#### *People who were homeless or at risk of homelessness*

People in the homelessness special needs group experienced significant benefits from highly tailored and flexible responses, the provision of 'wrap-around' supports from a range of other providers (including health care and supported or independent housing) with intensive case management by the CDC provider or sometimes in partnership with a homelessness outreach or supported housing provider.

The benefits experienced by people in this group were clearly related to having access to care and services (given that many of them had often had no access to health, community care or stable housing for many years), and access to case management support. Aside from the tailoring of the services and the inclusion of non-traditional services, such as direct health care, these benefits were not particularly associated with the CDC model.

Clients in this group expressed little interest in the individual budget and little desire to self-manage their package. It was clear from the interviews that they particularly valued the care planning and services offered by the CDC providers.

#### *People who were financially or socially disadvantaged*

There was little evidence from this group.

#### *Veterans and care leavers*

There was little evidence from either of these special needs groups. Take-up by people identifying as veterans or care leavers was relatively low.

#### *People living with dementia<sup>22</sup>*

Carers of people living with dementia indicated generally indicated a high level of satisfaction with CDC, most often related to the ability to ensure continuity of care workers and to exercise more control over the type of support worker (for example, level of skills, experience with dementia, personal rapport with the care recipient).

A number of carers of people living with dementia suggested that there were tangible benefits to the care recipient from having more tailored services – they were able to have support workers that they liked, and activities were structured around their personal interests and preferences.

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<sup>22</sup> People living with dementia are not a designated 'special needs group' under the Aged Care Act.

## 7 Impact of the initiative for CDRC participants and the people they care for

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### 7.1 Introduction

This chapter discusses the impact of consumer-directed care for CDRC participants and the people they care for. In particular, it addresses two key evaluation questions in relation to CDRC:

1. *To what extent was CDRC person-centred, and how did it increase choice and control for participants and the people they cared for?* This included participant satisfaction with the level of control they were able to exercise, their choice of services and service providers (including adequacy of support and information to make informed choices), their freedom to change services or service providers, and the satisfaction with CDRC.
2. *To what extent did CDRC enhance community-based care for participants and their carers?* This included the extent to which CDRC helped participants to achieve their personal goals, the impact of CDRC on perceived quality of care, quality of life and general health and wellbeing.

Evidence presented in this chapter is based on information gathered during interviews with CDRC participants, interviews with CDRC providers, and a survey of CDRC participants and an equal number of consumers who were accessing respite and other supports through NRCP.

Detailed data from the participant surveys is provided in Appendix B of this report.

### 7.2 Extent to which CDRC was person-centred and increased choice and control

#### *Involvement in planning and decision-making*

##### *Nature of involvement in care planning and budget planning process*

As discussed in chapter 3, planning for CDRC participants had a strong goal focus, and CDRC participants were heavily involved in the planning process. Typically, this involved a series of one-on-one discussions with a coordinator, with some participants needing more time for thinking about what they wanted to do or achieve and what they wanted to use their package for, though others were very clear and could quite clearly articulate what they wanted to use their package for in one meeting.

Discussions about the budget and the cost of supports were an integral part of the planning process – though they came at a later stage once participants had identified what they wanted to do or achieve, and had identified the types of supports they wanted to use.

Both providers and participants interviewed stated that the planning process was driven by the coordinator – and providers typically had their own specific ‘process’ which they were following. However, providers stated that participants were very much at the centre of discussions, and the majority of participants interviewed were satisfied with their involvement in the planning

process. Many noted that this was not something they could do themselves – the coordinator had a key role in helping them identify their goals as well as how they could best use their package. Many carers appreciated the suggestions and options that the coordinator gave about specific supports and how they might be delivered.

One of the common themes from participant interviews was that for many carers it was difficult initially to think about themselves and what they needed and wanted, rather than focussing only

*“It allowed me to be more my own person”*

CDRC participant

on the person they cared for. This was particularly apparent for long-term carers and older carers. Many carers had become accustomed to thinking only about the person they care for and arranging their lives around this person, and typically arranged activities (like shopping, household chores, social activities) around the schedule of the person they cared for. Simply getting used to the idea that the CDRC package was *for them* – the carer – and not the person they care for took time for many carers. Thinking about what they wanted to do or achieve with the package was also difficult for some carers, given they were not used to thinking about themselves and their lives. For these carers, the approach

and support provided by the coordinator was particularly important – to give them time to consider what they wanted from the package, and to build their capacity and confidence in speaking for themselves.

Carers who were particularly stressed or in-crisis at the time the package was offered found it more difficult to engage in the planning process, and for them, the initial contact and discussions with the coordinator was more about being supported by the coordinator and building trust with the coordinator. For these carers, it was important to put some regular supports in place quickly and then focus on planning and how they might want to use their package.

#### Example – immediate response

A woman who had been caring for her mother with dementia for a relative short period was finding it increasing difficult to cope as her mother’s condition deteriorated. She knew nothing about dementia and was not receiving any support prior to receiving a CDRC package.

The CDRC provider organised residential respite care for her mother to enable the carer to attend a weekend retreat, where she was able to learn about dementia and how to manage behavioural and physical support needs, as well as meet other carers of people living with dementia.

#### Budgeting

Many carers were attracted to the notion of having a set amount of funding which they had control over, and appreciated the transparency that this along with information on service costs provided.

Budgeting aspects were a key part of the planning process – particularly in the latter stages – though as for CDC participants, CDRC participants varied in their level of interest in the detailed budgeting and package allocation, with many carers focussed on what they could access with the funding rather than the detailed budgeting and package allocation. Older carers, people who had little experience with accessing formal services, and those who were in stress or who had recently been in crisis were typically less interested, and left it to coordinators to do the budget and allocate the package. Some carers – particularly those who were more financially savvy and

those who were able and wanted to self-manage, were more interested in the details of the budgeting process and in the costs of supports.

It should be noted that many CDRC participants thought that the package was relatively generous – particularly during the period of the evaluation when participants had a full year's allocation (\$4,200) to spend in six months or less. While participants were making decisions and trade-offs in terms of how to spend their package, 'difficult' decisions did not need to be made given the quantum of funds available, and as a result participants may have been less interested in the budgeting aspects of the package than if the package was to be used over an annual period (which will occur for 2011-12 and subsequent years).

#### *Involvement of the people being cared for*

Involvement of the person being cared for in the planning process differed across participants – though it is important to note that it was the carer's choice whether to involve the person they cared for, and this invariably was driven by the person's capacity to participate and the nature of the relationship they had with the person.

Many carers chose not to involve the person they care for, and the carer and coordinator arranged planning discussions at times when the person being cared for was somewhere else – so that the carer was able to focus fully on the planning discussion. For many of these carers, it was important *not* to involve the person they care for in the planning discussions to reinforce the notion that the package was for them – the carer. Typically, carers who were caring for someone with dementia, or who were carers of a parent or older spouse, chose not to involve them directly in planning discussions. However, in many cases the person they cared for was consulted about what would be happening, and at the very least, the needs and preferences of the person they cared for were taken into account in the discussions.

Other carers did involve the person they care for in discussions, though generally not as an active participant, and the skill and approach of the coordinator was important to maintain the focus on the carer. Typically, a person caring for their spouse would involve their spouse in discussions, where their spouse had the capacity to be involved, and especially where the couple had always made decisions as a unit rather than individually.

#### *Level of satisfaction with the planning process*

Overall, the level of satisfaction with the planning process, including the level of participant involvement and the extent to which their needs and goals were taken into account, was very high for CDRC participants and considerably higher than the NRCP comparison group, based on survey responses received:

- 66% of CDRC respondents strongly agreed with the statement *"I felt included in the process of planning my respite services"*, and a further 27 per cent agreed with this statement. This is considerably higher than for the NRCP comparison group (22 per cent strongly agreed and 62 per cent agreed with the statement).
- 67% of CDRC respondents 'strongly agreed' with the statement *"My needs and goals were taken into account in the process of planning my respite services"*, compared with only 20% of carers in the NRCP comparison group. However, there was a high proportion of comparison group respondents who 'agreed' with this statement (62%).

These points are illustrated in the tables below.

*Table 28: I felt included in the process of planning my respite services*

Response	CDRC	Comparison
Strongly disagree	1%	4%
Disagree	2%	2%
Neither agree nor disagree	2%	4%
Agree	27%	62%
Strongly agree	66%	22%

Based on responses received from 92 CDRC participants and 55 NRCP (comparison group) recipients  
 'Don't know', multiple and blank responses have not been reported in this table.

Source: CDRC and comparison group surveys, conducted August 2011.

*Table 29: My needs and goals were taken into account in the process of planning my respite services*

Response	CDRC	Comparison
Strongly disagree	2%	4%
Disagree	2%	5%
Neither agree nor disagree	2%	5%
Agree	26%	62%
Strongly agree	67%	20%

Based on responses received from 92 CDRC participants and 55 NRCP (comparison group) recipients  
 'Don't know', multiple and blank responses have not been reported in this table.

Source: CDRC and comparison group surveys, conducted August 2011.

*Table 30: I am satisfied with the way my respite care is planned and coordinated*

Response	CDRC	Comparison
Strongly disagree	2%	4%
Disagree	3%	7%
Neither agree nor disagree	1%	5%
Agree	40%	53%
Strongly agree	51%	27%

Based on responses received from 92 CDRC participants and 55 NRCP (comparison group) recipients  
 'Don't know', multiple and blank responses have not been reported in this table.

Source: CDRC and comparison group surveys, conducted August 2011.

### *Benefits of involvement in care planning and budgeting*

One of the main benefits of CDRC was the ability for a carer to plan regular support in advance – to enable them to take a break and to do the things they wanted and needed to do. There was a definite shift in focus compared with NRCP from more short-term, emergency and sometimes intensive respite to regular less intensive support (including respite). This has considerable impacts on CDRC participants' quality of life and wellbeing, their social connections and relationships and participation in social and community activities. This is discussed further in section 7.3.

There were also benefits from merely *being involved* in planning. For carers, simply having a conversation with someone about what they wanted and needed and being able to make some decisions about their life was one of the main benefits of CDRC and of being involved in planning. For many carers, this was the first time that this had occurred and the first time that someone was focussing on them as carers rather than focussing on the person they care for. Regardless of the planning outcome or the supports that were put in place, a common theme from interviews was that carers felt recognised and valued, and that *they* were important, and this in itself had an impact on their capacity and commitment to continue with their caring role.

*"It makes a big difference to have someone there to talk to. Sometimes I feel very lonely, but (the coordinator) is always there, and she always has good advice."*

CDRC participant caring for her mother

A number of participants highlighted developing a strong relationship with the CDRC coordinator, and considered this relationship to be an important source of emotional support and advice on a wide range of issues related to the participant's caring role. In particular, the strength of this relationship, together with the effectiveness of the coordinator's skills and approach, was important for many CDRC participants in building their capacity to self-identify needs and goals, and for some carers to build their capacity to take on more of the management and coordination of their package themselves.

### *Extent of participant 'choice'*

#### *Choices available to participants*

Providers stated that CDRC provided greater choice and flexibility for participants than NRCP, and noted that CDRC was not constrained by predetermined service types and rules around what can and cannot be funded in the same way that NRCP is constrained.

Planning and decision-making process was more complex than choosing from a 'menu'. As stated earlier, it was more common for CDRC providers to take a goal-focussed approach to planning, and there was heavy focus on identifying participants' goals in the planning phase. This approach meant that invariably participants were not choosing from a menu of predetermined service types, but rather were identifying what they wanted to be able to do or achieve and then identifying the nature of the support they wanted and what these supports looked like.

This meant that notions of 'choice' of supports were intertwined with notions of the supports participants wanted to access and 'input' into and 'control' over the design and delivery of these supports. A common scenario was a participant wanting to have regular time for themselves so

they could do what they needed and wanted to do. This might be a day per month or a morning or afternoon each week so they could go to their bridge club, to a yoga class, to visit family or spend time with friends. In these situations they typically wanted a support worker to come to their home and spend time with the person they care for, prepare a meal, or do some housework. They would decide when the support worker would come, how long the support worker would stay, and what the support worker did while they were in their home. They may even decide which support worker they want – based on support workers already known to them, or after trialling a few support workers to determine who they had most confidence in and who got along well with the person they cared for. In this scenario there were elements of choice (of support worker), and of control and input into how the supports were delivered (that is, the day and time, and the tasks the support worker had).

Many participants felt that they had increased level of comfort with formal care, and ‘peace of mind’ and that the person they care for was being looked after, as a result of being able to choose their supports and support worker, and in particular choosing in-home support rather than using residential respite.

Participants also were able to ‘choose’ the traditional types of services such as residential respite that were available under NRCP and other community care programs, though were also able to use their package innovatively and flexibly to purchase non-traditional supports – which were not available under NRCP. Further, there was more scope to choose types of support that were difficult to access under NRCP (because of limited funding or services), such as regular in-home respite or in-home support, and more scope to influence or decide how supports were delivered (such as choice of support worker).

Providers stated that they were open and flexible to non-traditional support types, and participants stated that in general they were able to access the supports that they wanted. A few participants provided examples where providers did not allow them to choose specific types of support – primarily those supports that are not traditionally funded under NRCP or other respite programs. This may have been due to a lack of flexibility on the part of the provider, or the provider’s interpretation of the guidelines (both correct and incorrect interpretations).

Participants felt that CDRC providers were generally flexible and open to arranging a wide range of supports which would enable them to do what they wanted to do – there were numerous examples of flexible supports and creative or ‘non-traditional’ use of packages – as outlined in the box below.

#### ***Examples of creative or ‘non-traditional’ use of CDRC package funds***

An Aboriginal man who was caring for his wife used part of his CDRC package for petrol to enable him to drive him and his wife to visit his wife’s family – hundreds of kilometres from where he and his wife lived. The journey allowed his wife to spend time with her family in the place where she came from, as well as providing the man with a break from his full-time caring role as family members took on more of the caring tasks.

A woman who cared for her husband who had dementia used her CDRC package for her husband to go the local Men’s Shed– a place where he enjoyed going – for four hours each day. As her husband’s dementia deteriorated she found it more difficult to care for him, and the four hours each day provided her with the break she needed to be able to continue in her caring role. She used the break each day to do household chores, run errands, and meet friends. She said that if it weren’t for her CDRC package and the Men’s Shed, she would have had to place her husband in residential care.

A CDRC participant who was caring for her father who had dementia used part of her package for a gym membership for herself and her mother. Going to the gym allowed the daughter and mother to spend time together and to 'reconnect' outside of their home environment.

A CDRC participant from a CALD background used part of her package to purchase a pay-television subscription so that her mother, who she cared for, was able to watch programs in her native language. The participant saw this as a form of respite for herself, as well as allowing her mother to do something she enjoyed.

A participant in her 60s who cared for her mother used some of her CDRC package for a holiday so she could visit her son and grandchildren. She used the package to pay for a return airfare, as well as for in-home support for her mother who remained at home – a few hours in the morning and a few hours in the evening. She also arranged for neighbours and other relatives to visit her mother regularly while she was away.

A CDRC participant used part of her package for a holiday with her husband who she cared for. To assist with holiday expenses, the CRCC opened a bank account for the carer. The CRCC deposited funds into the bank account, and the carer was able to withdraw funds as needed during the holiday. The carer had the only card, and provided receipts to the CRCC.

For small items of expenditure, CDRC providers utilised vouchers (coffee, petrol, taxi), or reimbursed participants in cash.

However, there were some examples of providers refusing to fund specific supports or goods, and there was some inconsistencies between providers relating to what providers allowed participants to use their package for, including many of the examples highlighted above.

Survey responses indicated that CDRC participants were very satisfied with the choice of supports, and the assistance they received from the CDRC provider to make decisions about the types of supports they access:

- 88 per cent of CDRC survey respondents agreed or strongly agreed with the statement *"The Commonwealth Respite and Carelink Centre helped me to plan and make decisions regarding the types of respite services I could choose"*.
- There were similar levels of agreement with the statement *"I was satisfied with the range of respite services that I could choose"*, though a greater proportion (46 per cent) strongly agreed with this statement compared with the NRCP comparison group.

This is illustrated in the tables below:

*Table 31: The Commonwealth Respite and Carelink Centre helped me to plan and make decisions regarding the types of respite services I could choose*

	CDRC
Strongly disagree	2%
Disagree	2%
Neither agree nor disagree	3%
Agree	33%
Strongly agree	55%

Based on responses received from 92 CDRC participants and 55 NRCP (comparison group) recipients

'Don't know', multiple and blank responses have not been reported in this table.

Source: CDRC and comparison group surveys, conducted August 2011.

*Table 32: I was satisfied with the range of respite services that I could choose*

	CDRC	Comparison
Strongly disagree	2%	5%
Disagree	8%	9%
Neither agree nor disagree	7%	2%
Agree	33%	62%
Strongly agree	46%	16%

Based on responses received from 92 CDRC participants and 55 NRCP (comparison group) recipients

'Don't know', multiple and blank responses have not been reported in this table.

Source: CDRC and comparison group surveys, conducted August 2011.

It is important to note that there were some limitations on participant choice imposed by the guidelines – both intended and unintended. A number of providers stated that the requirement that every support provider and support worker have a police check limited choice of non-traditional supports to some extent – for example, where a carer wanted to use the services of a taxi driver known to them on a regular basis, or the services of a garden maintenance provider, where these people did not have police checks. Further, the Department discouraged the employment of family members to provide care, though this did not feature as a significant issue.

### *Choice of support provider*

All providers interviewed stated that they had agreements in place with a number of service providers to provide respite and other supports to NRCP clients, and providers used these agreements to broker services for CDRC participants in the same way as they do for NRCP clients. From a provider perspective, this provided a range of providers from which CDRC participants could choose to access services from. Where participants wanted other types of support or wanted to use their package for services not generally funded under NRCP (e.g. airline tickets for holidays, petrol vouchers), service providers stated that they would deal with the providers directly and either purchase the good/service, or seek quotes for the good/service and then pay for the one the participant wanted. Generally, these were 'one-off' cases, and did not require formal, ongoing agreements to be put in place.

Choice of service provider did not appear to be as important to most participants interviewed as the choice of service or the input that they could have in designing the supports. This was especially the case where they had no prior experience of respite or other services. Where they had had some experience, carers may have wanted to utilise a particular support worker with whom they had worked before. A number of participants who used residential respite (and had used it previously) had strong preferences to use, or not use, particular residential respite providers – based on their previous (good or bad) experiences or what they knew about the providers.

In some cases, participants had done their own research into which support providers were available, or discussed the available support providers with their CDRC provider. This was the exception, however, and tended to be younger carers who took this course of action (that is, people caring for their mother or father, or caring for their older spouse). Very few participants stated they spoke with support providers directly, other than residential respite providers.

Unlike CDC providers, most CDRC providers did not have any significant in-house services that were available to CDRC participants, hence most supports were purchased or brokered from other organisations (in the same way that supports were purchased or brokered under NRCP). CDRC providers in the main used agreements with support providers that were already in place (for NRCP and other programs) to facilitate this, and at a minimum, CDRC participants were able to choose to receive supports from these providers. However, some providers stated that they used support providers with whom they did not have formal agreements in place to provide specific supports – mainly non-traditional supports, one-off purchases of goods or services (such as incontinence products, airline tickets), or common services that were readily available (such as taxis, garden maintenance).

### ***Ability of participants to make informed choices***

Providing real choice to participants was dependent on participants being aware that they had choices and that they had the necessary information to make informed choices. As noted above there was clear evidence of providers using a goal based approach to planning and working with participants to identify appropriate supports. However, participants did not necessarily know what supports were available or from whom, and relied on the CDRC provider to give them this information, to take them through support options, and to make suggestions regarding support options.

The majority of service providers did not provide detailed written information to participants on support options and support providers, and some providers did not provide any written information to participants. Instead, there was a predominant view that participants should not be unnecessarily burdened or overwhelmed with information, and the majority of providers provided information verbally (on support options and support providers) during planning discussions, though some provided some high-level written information. It is not clear whether providers modified the level of information they provided to individual participants to suit the participant's level of interest or capacity or need for information (for example, high level verbal information for participants whose needs and wants were clear or who were not actively involved in planning, detailed written information for participants who were actively involved and with an interest in self managing their package).

Based on the information collected, information on quality of services did not seem to be provided to participants.

Certainly, the majority of CDRC participants were satisfied with the level of information they received and relatively few stated that they wanted more information than they received, though it is difficult to say whether providing more (or less) information would have any impact on participants' level of satisfaction or the decisions they had made.

CDRC survey respondents' level of agreement with statements relating to the adequacy of information provided on types of supports, support providers and support costs that participants could choose indicated high levels of satisfaction (tables B.82-84).

### ***Extent of participant 'control' over the services they accessed***

As noted above, notions of control and input into the supports that participants identified were intertwined with notions of choice. Typically, participants had input during the planning process into the way that their supports would be delivered, who would provide them (that is, choosing a support worker or trialling a small number of support workers), the days and times when they access support and in some the nature of the tasks to be undertaken by support workers or providers.

On an ongoing basis, participants also had a degree of control and input into how their supports were delivered where this was necessary – for example, being able to change the day or time when they accessed support, or direct a support worker to undertake different tasks (in much the same way as CDC participants). In a number of cases, participants would deal directly with the support worker or support provider themselves, though it was not uncommon for participants to ask their coordinator to do this for them.

There was a considerable level of agreement with the statement *"I feel like I have control over my respite plan, and the respite services I receive"* among both the CDRC and NRCP comparison group survey respondents, though stronger agreement among CDRC respondents.

*Table 33: I feel like I have control over my respite plan, and the respite services I receive*

	CDRC	Comparison
Strongly disagree	1%	5%
Disagree	3%	15%
Neither agree nor disagree	8%	7%
Agree	37%	55%
Strongly agree	48%	13%

Based on responses received from 92 CDRC participants and 55 NRCP (comparison group) recipients

'Don't know', multiple and blank responses have not been reported in this table.

Source: CDRC and comparison group surveys, conducted August 2011.

Once supports were in place, it was uncommon for participants to make major changes to their arrangements, unless they were particularly dissatisfied with their current supports or support worker. This was particularly important for CDRC participants caring for someone with dementia, where the participant would "try out" several support workers until they found one the person they cared for was comfortable with. When major changes needed to happen, participants generally felt comfortable in speaking to their coordinator to request a change in their support arrangements, or making the change themselves.

The vast majority of CDRC and NRCP comparison group survey respondents felt comfortable in changing the types of services they received if they needed to, with the CDRC group more comfortable – as illustrated in the table below.

*Table 34: I would feel comfortable asking to change the type of services that I receive if I needed to, or asking for a new type of service*

	CDRC	Comparison
Strongly disagree	1%	4%
Disagree	2%	5%
Neither agree nor disagree	0%	5%
Agree	41%	56%
Strongly agree	51%	24%

Based on responses received from 92 CDRC participants and 55 NRCP (comparison group) recipients

'Don't know', multiple and blank responses have not been reported in this table.

Source: CDRC and comparison group surveys, conducted August 2011.

#### *Extent to which participants were able to self-manage their package*

As for CDC, most participants identified being able to make simple changes to their support arrangements (e.g. change time of support worker coming), though typically participants relied on their coordinator to make more substantial changes (such as changing the days support workers came, or changing the nature of support accessed).

Some providers encouraged participants to build their capacity to self-manage their package and take on more responsibility for managing their package and support arrangements, though providers had mixed success with this. However, as for CDC, a number of providers did not offer this as an option, preferring to manage the packages and coordinate support arrangements on behalf of their participants.

Many participants had no desire to manage more of their package themselves (or simply had not thought about it), did not want the responsibility or burden, or did not think they had the capacity. Younger carers and people new to a caring role were more likely to want to self-manage to some extent, and a small number wanted to be completely responsible for managing their package (dealing with support providers and paying for supports directly, rather than relating on a provider to do this for them).

#### Key points – Person-centredness, choice and control

- Overall there was a high degree of participant satisfaction with the CDRC approach and model – and in particular the flexibility that CDRC provides and the planned nature of supports.
- There were considerable benefits for carers from being able to plan supports in advance, and from simply being involved in the planning process. For many carers, they felt that they were being recognised and valued as carers – often for the first time.
- CDRC allowed carers to focus on themselves, rather than the person they care for. Most actively were actively involved in planning, though for some it took a while to determine what they wanted to use their package for.
- Many carers involved the people they cared for in planning discussions, though generally they were not actively involved in planning – the focus of planning was very much ‘carer-centred’.
- The relationship with the coordinator was particularly important for many carers. The strength of this relationship (and the effectiveness of the coordinator’s skills) seemed important for clients in building their capacity to self-identify needs and goals, building their capacity to self-direct, and receiving emotional support and advice on a wide range of issues related to their caring.
- CDRC provided more choice of supports and more control and influence over the supports carers received than other community care programs that carers had experience with. In particular, participants tended to choose in-home and flexible supports which enabled them not only to ‘take a break’ but also to do the things they wanted to do, including social activities and spending more time with their own family. Only a small proportion of participants chose to use residential respite.
- Many participants also used part of the package funding for ‘non-traditional’ supports, goods and services such as holidays, gym memberships, television subscriptions, continence products, and petrol.

## 7.3 Extent to which CDRC enhanced community-based care

### *Impact on quality of care*

While there was a high degree of satisfaction with the quality of supports that participants and the people they cared for received, it needs to be noted that the majority of participants were receiving low-level or no supports prior to commencing a CDRC package. This meant many participants had no point of comparison. Further, the level of resources available to them is likely to have influenced their perspectives of ‘quality’.

As for CDC, CDRC participants considered that their ability to choose the supports they accessed and their ability to control and influence the way supports were provided to better suit the carer’s (and care recipient’s) needs had a positive impact on the quality of supports. A number of participants highlighted the choice of support worker as particularly important, as well as the freedom to choose supports that the person they care for was happy with. A number of participants highlighted the fact that they were now able to access supports other than residential respite, which was often cited as being of poor quality and in some cases upsetting and even traumatic for the person they cared for.

There was a considerably greater level of satisfaction with the quality of supports received by the CDRC group compared with the NRCP comparison group, as illustrated in the table below.

*Table 35: Overall, I am satisfied with the quality of respite services I receive*

	CDRC	Comparison
Strongly disagree	1%	4%
Disagree	2%	4%
Neither agree nor disagree	2%	9%
Agree	37%	45%
Strongly agree	55%	31%

Based on responses received from 92 CDRC participants and 55 NRCP (comparison group) recipients

'Don't know', multiple and blank responses have not been reported in this table.

Source: CDRC and comparison group surveys, conducted August 2011.

### ***Assisting participants to achieve their personal goals***

As noted earlier, CDRC had a strong goal focus and the majority of providers used a 'goal-oriented' approach to planning. Participants goals were relatively simple, such as having regular time for themselves (a day each week, or a few hours each day), or to spend more time with or visit family and friends. For most participants, their goals were much more than simply 'having a break' from caring.

Some carers found it difficult to know what they needed and wanted, and took time to get used to the idea that the package was about them and to identify what they needed/wanted. This was particularly the case for participants who were older and participants who had been in a caring role for a long period of time. Younger carers and those who had not been in the caring role for very long were more definite about what they wanted.

Almost without exception, participants felt that the package enabled them to do some of the things they wanted to do or achieve: 53 per cent of CDRC survey respondents were much more satisfied with their ability to achieve the things they wanted to achieve compared with six months prior, compared to only 20 per cent of the NRCP comparison group. This is illustrated in the table below.

*Table 36: Compared to six months ago, how satisfied were you with your ability to achieve the things you want to achieve?*

Response	CDRC	Comparison
Not satisfied	3%	13%
Somewhat less satisfied	3%	15%
No different	14%	35%
Somewhat more satisfied	23%	20%
Much more satisfied	53%	13%

Based on responses received from 92 CDRC participants and 55 NRCP (comparison group) recipients

'Don't know', multiple and blank responses have not been reported in this table.

Source: CDRC and comparison group surveys, conducted August 2011.

### *Impact on quality of life, health and wellbeing*

There was clear evidence that CDRC had a considerable positive impact on carers' participation in social and community activities, their home life and close relationships, level of independence, their health and wellbeing, and their capacity to continue in their caring role.

It needs to be noted that during 2010-11, participants had access to a full annual package amount (\$4,200) – to be spent in six months or less. This enabled participants to access supports at greater levels than would be possible if they had a package over a full year, and this is likely to have had an impact on the scale of benefits experienced by CDRC participants during the period of this evaluation.

However, it should also be noted that the benefits experienced by participants were evident in a relatively short time period following commencement.

*"CDRC has given me a new sense of freedom – it makes a big difference to know if something comes up that I want to do, I can actually do it."*

CDRC participant  
aged in her 40s

### *Capacity to continue in their caring role*

Many participants felt that their capacity to continue in their caring had increased since commencing on the package, and for many having a package gave them a chance to put energy back into their caring role. Participants also felt more valued and recognised as carers (many for the first time), and an increased sense of self from being able to focus on themselves and their lives rather than only on the people they care for.

### *Independence*

A number of participants also spoke about an increased level of independence, and ability to do the things they wanted and needed to do without being overly burdened by their caring role, or feeling guilt or regret when they did things for themselves.

Compared with the NRCP comparison group, there was a increased level of satisfaction among CDRC participants with their level of independence (58 per cent somewhat more satisfied or much more satisfied with their level of independence compared with six months prior). This was considerably higher than the NRCP comparison group where levels of satisfaction were low (24 per cent somewhat more satisfied or much more satisfied). This is illustrated in the table below.

*Table 37: Compared to six months ago, how satisfied were you with your level of independence?*

Response	CDRC	Comparison
Not satisfied	3%	13%
Somewhat less satisfied	5%	18%
No different	29%	45%
Somewhat more satisfied	36%	15%
Much more satisfied	22%	9%

Based on responses received from 92 CDRC participants and 55 NRCP (comparison group) recipients

'Don't know', multiple and blank responses have not been reported in this table.

Source: CDRC and comparison group surveys, conducted August 2011.

### *Participation in social and community activities*

Participants identified that they were more able to participate in social activities, including spending time with friends, attending classes or regular club events, and spending more time on recreational activities (such as the theatre/cinema, sporting events, going to church), and being able to do things during weekends. Many participants were able to 'rediscover' activities that they enjoyed but had been unable to do because of their caring role.

There was an increased level of satisfaction among CDRC participants who responded to the survey with their ability to participate in social and community activities compared with six months ago (with 63 per cent somewhat more satisfied or much more satisfied compared with six months prior). This was considerably higher than the NRCP comparison group where levels of satisfaction were low (30 per cent somewhat more satisfied or much more satisfied). This is illustrated in the table below.

*Table 38: Compared to six months ago, how satisfied were you with your ability to participate in social and community activities?*

Response	CDRC	Comparison
Not satisfied	3%	16%
Somewhat less satisfied	8%	15%
No different	20%	36%
Somewhat more satisfied	28%	25%
Much more satisfied	35%	5%

Based on responses received from 92 CDRC participants and 55 NRCP (comparison group) recipients

'Don't know', multiple and blank responses have not been reported in this table.

Source: CDRC and comparison group surveys, conducted August 2011.

## Relationships

A number of participants also identified that having a package improved the relationship not only with the person they cared for, but also with members of their own immediate family and other significant people in their lives, such as siblings, their children and grandchildren, and in some cases their partner. In part this was due to being able to spend more time with their family and other significant people in their lives, but also because the package gave them a 'lift' and increased their level of wellbeing and life satisfaction – given them renewed energy and motivation to dedicate to their close relationships.

*"My grandchildren would call and ask me to do things. I'd always have to say no. One day, one of them called me up and said 'oh I suppose you can't come again Nan', but this time I could come! They were so excited, and I was too."*

CDRC participant aged in her 70s, who had been caring for her husband for 10 years

From survey responses, it is clear that there was a higher level of satisfaction among CDRC participants compared with NRCP recipients with the quality of their home life and the extent to which they could visit family and friends:

- 58 per cent of CDRC respondents were somewhat more satisfied or much more satisfied with the quality of their home life and close relationships compared with six months prior, though only 29 per cent of the NRCP comparison group were somewhat more satisfied or much more satisfied.
- 55 per cent of CDRC respondents were somewhat more satisfied or much more satisfied with the extent to which they were able to visit family and friends compared with six months prior. Only 29 per cent of the NRCP comparison group indicated that they were somewhat more satisfied or much more satisfied, and for a third there was little difference.

This is illustrated in the tables below.

*Table 39: Compared to six months ago, how satisfied were you with the quality of your home life and close relationships?*

Response	CDRC	Comparison
Not satisfied	5%	11%
Somewhat less satisfied	5%	16%
No different	27%	42%
Somewhat more satisfied	32%	20%
Much more satisfied	26%	9%

Based on responses received from 92 CDRC participants and 55 NRCP (comparison group) recipients

'Don't know', multiple and blank responses have not been reported in this table.

Source: CDRC and comparison group surveys, conducted August 2011.

*Table 40: Compared to six months ago, how satisfied were you with the extent to which you were able to visit your family and friends?*

	CDRC	Comparison
Not satisfied	3%	15%
Somewhat less satisfied	2%	13%
No different	33%	44%
Somewhat more satisfied	28%	18%
Much more satisfied	27%	9%

Based on responses received from 92 CDRC participants and 55 NRCP (comparison group) recipients

'Don't know', multiple and blank responses have not been reported in this table.

Source: CDRC and comparison group surveys, conducted August 2011.

### *Health and wellbeing*

There is evidence that CDRC also had an impact on participants' health and wellbeing. Some participants interviewed stated that their physical health had improved, given they were able to use their package for activities with direct health benefits (such as gym memberships, Pilates and yoga classes), and for respite supports to enable them to participate in these activities. The main impact, however, was on carers' mental and emotional health and sense of wellbeing. Participants identified decreased levels of stress, resentment, and depression, a more positive outlook on life and renewed energy and vigour.

This is reflected in survey results. Half of CDRC respondents were somewhat or much more satisfied with their general health and wellbeing compared to six months prior – considerably higher than the NRCP comparison group (16 per cent). This is illustrated in the following table.

*"For so long I knew what I needed to do every day. Suddenly, I could do other things, different things. I had something to look forward to".*

Long-term carer

*Table 41: Compared to six months ago, how satisfied were you with your general health and wellbeing?*

Response	CDRC	Comparison
Not satisfied	3%	11%
Somewhat less satisfied	8%	36%
No different	36%	36%
Somewhat more satisfied	30%	11%
Much more satisfied	20%	5%

Based on responses received from 92 CDRC participants and 55 NRCP (comparison group) recipients

'Don't know', multiple and blank responses have not been reported in this table.

Source: CDRC and comparison group surveys, conducted August 2011.

### Measure of wellbeing

As for the CDRC and packaged care comparison group surveys, the CDRC and respite comparison group surveys also included a partial measure of outcome – the ICECAP-O wellbeing measure.<sup>23</sup>

The median ICECAP-O scores for the CDRC and respite comparison group are outlined in the table below. As the table shows, the CDRC group scored marginally higher than the respite comparison group, indicating slightly higher wellbeing in the CDRC group, though these differences were not statistically significant.<sup>24</sup>

Table 42: ICECAP-O wellbeing tool – average scores

	CDRC	Comparison
<b>Median score</b>	<b>0.76</b>	<b>0.71</b>

A score of 1 is the maximum wellbeing score, and a score of 0 the minimum.

Source: CDRC and comparison group surveys, conducted August 2011. Scores are based on responses received from 92 CDRC participants and 55 NRCP (comparison group) recipients. Note that respondents who did not complete all five items have been excluded.

### Key points – Enhancing community-based care

- Even after a short period of operation, CDRC had a considerable positive impact on carers. Many participants felt that their capacity to continue in their caring had increased since commencing on the package, and for many having a package gave them a chance to put energy back into their caring role.
- Almost without exception, participants felt that the package enabled them to do many of the things they wanted to do or achieve.
- There was a considerable positive impact on carers' participation in social and community activities, their home life and close relationships, level of independence, and health and wellbeing. Participants also experienced an increased 'sense of self', and a sense of greater wellbeing. However, using a validated measure of wellbeing, there was no statistically significant difference between the CDRC participant group and carers accessing supports through NRCP.
- It needs to be noted, however, that during the period of the evaluation participants had access to a full annual package amount (\$4,200) – to be spent in six months or less - and this is likely to have had an impact on the scale of benefits experienced by CDRC participants.

<sup>23</sup> The 'ICEpop CAPability measure for Older people' (ICECAP-O) is a validated measure of wellbeing in older people. The ICECAP-O tool uses a definition of wellbeing which is broader than most other measurement tools (which focus on health and/or functional capability), and covers five attributes of wellbeing that were found to be important to older people in the UK: *Attachment* (love and friendship), *Security* (thinking about the future without concern), *Role* (doing things that make you feel valued), *Enjoyment* (enjoyment and pleasure), *Control* (independence). The ICECAP-O tool provides a single wellbeing score (between 0 and 1) for each individual completing the five-question tool. Source: <http://www.icecap.bham.ac.uk/ICECAP-O/index.shtml>, accessed September 2011.

<sup>24</sup> using the Mann-Whitney test for non-normally distributed data, p=0.05

## 7.4 Benefits for care recipients

A number of CDRC participants identified that their relationship with the person they cared for had improved since receiving a CDRC package. Having the package had allowed them to focus more on themselves, and participants spoke of feeling less stressed, less burdened, and more satisfied with life – which impacted on their interaction with the person they cared for. Some carers also identified that prior to receiving the package, they had come to ‘resent’ their caring role (and in some cases felt guilty about feeling this resentment) which was having a negative impact on the person they cared for, and having the package allowed them to feel less resentful and more recognised and valued in their caring role.

*“I use my package to take regular breaks, to go out and do my own thing. I have more energy for my mother now, and can give her a bit of extra TLC. I’m much more patient with her too”.*

CDRC participant caring for her mother who had dementia

There were also more direct benefits for the people CDRC participants were caring for. The increased choice and flexibility of packages allowed participants to put in place supports which were more acceptable for the person they cared for. A common example was the ability to use the package for regular in-home support provided by a support worker who the care recipient liked and got along well with. In many cases, this was used as an alternative to residential respite (which may have been the only form of respite they had accessed previously), which many participants were averse to because it was stressful, problematic and sometimes traumatic for the person they cared for.

Many participants used the package for out-of-home support and activities for the person they cared for, such as day centres and men’s sheds. Again, participants chose activities that the person they cared for liked and enjoyed and which provided them with some social contact, as well as providing a break for the carer. Participants highlighted that prior to receiving the package they were not able to access these supports, or were simply unaware that they existed.

## 7.5 Considerations for special needs groups

It is not possible to draw any conclusions relating to benefits and impacts of CDRC for a number of special needs groups – including participants from Aboriginal or Torres Strait Islander backgrounds, veterans, those who are homeless or at risk of homelessness, and care-leavers – given their low representation in the CDRC participant group and their low representation in the evaluation data collection.

However, a number of considerations and observations can be made – as discussed below.

#### *People from Aboriginal or Torres Strait Islander backgrounds*

There was a very low take-up rate of CDRC by carers from an Aboriginal and Torres Strait Islander background. Like CDC, the cultural appropriateness of CDRC needs to be examined – particularly in the context of the focus on the individual rather than the family or community, and concerns about ‘humbugging’.

#### *People living in rural and remote areas*

There was no evidence of difference between CDRC participants living in rural and remote areas versus those in regional towns and metropolitan areas in terms of their involvement in or satisfaction with CDRC.

Some CDRC providers who had CDRC packages in rural and remote areas highlighted the benefit that packages provided in terms of ‘choice’. In rural and remote areas services were typically more limited, and the extent of choice was more limited – for example, some service types were not be available or difficult to access, others were available in a regional centre (requiring people to travel to access them), and there was less choice of providers or support workers. However, this applies equally to a range of community care services as well as CDRC (and CDC), and providers highlighted one of the benefits of a consumer-directed approach was that they were able to be more flexible and creative, and through this were able to provide greater choice for participants than they traditionally would.

#### *People from culturally and linguistically diverse backgrounds*

For participants (and the people they cared for) from a CALD background, the choice of support worker was highlighted as important – and in particular having the ability to choose a support worker who came from the same or similar cultural background and/or spoke the same language as the person being cared for, where they were available. Where a carer had identified this as important, often the CDRC provider had to spend some time finding an appropriate support worker.

#### *People who were financially or socially disadvantaged*

This group was difficult to identify, though a number of providers and participants identified themselves as financially or socially disadvantaged based on their own understanding of the term. A number of carers on limited incomes spoke of the benefit that CDRC provided them in being able to access supports which they would have not been able to access because of their limited ability to pay out of their own pocket. This is more related to the size of the CDRC package than the CDRC approach, however.

#### *Other special needs groups*

There were few or no participants who were homeless or at risk of homelessness, veteran (or spouses of veterans), or care-leavers.

## 8 Impact on providers and the broader service system

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### 8.1 Introduction

This chapter considers issues relating to the impact of the initiative on providers and the broader service system, including impacts on provider culture or approaches to standard packaged care or respite care.

### 8.2 Impact on CDC providers

CDC providers differed in the extent to which they considered that participating in the CDC pilot had changed their 'culture'. These positions are summarised below.

#### *'CDC is no different to standard packaged care – our approach is the same'*

A number of providers (generally, those that applied the menu-based planning approach) held that CDC in practice was not very different to standard packaged care, and would not change their overall approach. They suggested the main difference was giving the client more choice and provision of the individual budget, and some suggested that these mechanisms could be made available with relative ease under standard care packages if that is what people wanted, rather than having a special CDC package.

These providers usually indicated that the CDC experience would not change anything about their approach to standard packaged care, with one main exception. The focus on the individual budget had improved their coordinators' financial and budgeting skills, and this, along with the budget reporting tools and processes developed for CDC, meant that the organisation was better positioned to be more accountable to their standard care clients. Several providers indicated that they could, on request, use their CDC budget tools to provide more information about costs and expenditure to their standard care clients – but most did not propose to do that as a matter of course.

#### *'CDC has made some difference to how we think about what is possible'*

Some providers still felt that, by and large, CDC was no different from standard packaged care – particularly from the perspective of the participant or carer, and especially so for CDCL participants – but they did acknowledge that CDC had made an impact on the coordinators and managers in terms of their own thinking about 'what is possible' on a care package. This relates to more tailored services, informal services, and use of non-traditional supports.

These providers appeared to be moving towards the person-centred approach. Some of them had started to change their approach to standard packaged care by being more transparent about services and costs, trying a different approach to planning, and considering the use of individual budgets with some clients.

#### *'CDC has changed the way we approach standard packaged care'*

A small number of providers (those that applied the 'goal-based' approach to planning) felt that CDC was fundamentally different because of its enabling, strengths-based approach to planning and delivery of supports. These providers suggested that their CDC experience would most

certainly change their approach to standard packaged care clients in two key ways: first, by adopting an enabling approach to planning, and secondly, by focussing on participant and carer goals and framing supports around those.

Irrespective of which of these three positions CDC providers took when thinking about the extent to which CDC had influenced their culture, almost all providers agreed that CDC had made them more accountable for the costs of services, including the costs of their own administration and support coordination and management activities.

### 8.3 Impact on CDRC providers

All of the interviewed CDRC providers indicated that CDRC had a significant impact on their culture in two key ways. Firstly, CDRC was viewed as a considerably different service type which met the previously unmet needs of a particular client group, and so CDRC had effectively expanded the range and reach of services and supports offered by the provider. Secondly, CDRC had encouraged 'out of the box' thinking by approaching respite in new, innovative ways. This had a positive influence not only on the coordinators directly working on CDRC, but also on the wider staff of the CRCCs who felt they were making a positive difference in their clients' lives.

The difficulty for providers will be applying these new approaches in their NRCP business, given the significantly lower level of resources available to an individual.

### 8.4 Broader service system impacts

#### *ACAT acceptance of and support for CDC*

Some providers reported that there was initial resistance from ACATs at the commencement of CDC. Some ACATs were concerned that CDC would not provide the same level of support available under standard packaged care. These initial concerns appeared to have been overcome. Although ACATs do not assess a person for CDC, they can and did sometimes play a role in helping to identify new participants that might be suitable for CDC. A wider rollout of CDC should consider the information and education needs of ACATs.

#### *Brokered services agencies*

Several CDC and CDRC providers reported that some brokered services agencies with little experience of cost recovery had some challenges with the invoicing aspects of CDC. This may be an aspect that needs to be considered in a wider rollout of CDC.

A number of CDC providers also reported an initial hesitancy by some brokered services agencies to engage directly with the clients. Some CDC providers suggested that those agencies with experience of providing services to disability clients, and therefore previous exposure to self-managing clients, had no issues dealing directly with clients (rather than going through the CDC provider), but those agencies that only provide aged care services could be more reluctant. A potential challenge here is the impact of a greater number of self-managing clients all directly contacting agency providers as CDC expands.



### ***Broader interest in CDC***

It was clear from interviews with providers that there is a growing interest in CDC among the broader community care system, from other organisations, other staff within CDC organisations. The impact of this for providers involved in the CDC initiative is potentially a raised profile. The impact for the wider community aged care system will be an increasing demand for information about how CDC is working, and the models in place to implement it.

There is also growing interest in CDC from individuals, particularly younger carers who want more control (and who may be dissatisfied with current care arrangements). The impact of this will likely be an increasing demand for CDC and CDRC packages over time – as well as demand for more flexibility and greater control for the consumer within those packages. CDC will need to be responsive to those demands.

## 9 Cost assessment and cost-effectiveness of the initiative

### 9.1 Introduction

This chapter outlines the findings of a 'cost assessment' undertaken as part of the evaluation. This included an assessment of the cost to providers of setting-up CDC and CDRC, the ongoing costs of the initiative incurred by providers, the average fees charged to participants for administration and case planning and management (and the basis of these fees), and the extent to which costs incurred by providers were funded or recovered.

This chapter also outlines high-level observations in relation to the cost-effectiveness and financial sustainability of the initiative, and provides guidance for undertaking a full cost-effectiveness analysis once the initiative has been in operation for a longer period.

### 9.2 Provider set-up costs

CDC providers reported that they collectively spent approximately \$1 million in 2010-11 to develop and implement CDC within their organisation.<sup>25</sup> Set-up costs were not funded by the Department, and were met by providers themselves.

For CDC, the average set up costs per CDC package was approximately \$2,275 per package in 2010-11 (the period when the first round of packages were allocated to providers). The main cost items related to planning and to the development of modification of internal systems and processes.

CDRC providers reported that they collectively spent approximately \$200,000 in 2010-11 to develop and implement CDC within their organisation. The average set up costs per CDRC package was approximately \$1,098 per package. The main cost items related to planning, participant recruitment and development of information and other resources.

This is illustrated in the table below.

*Table 43: Estimated average set-up costs per CDC package incurred by CDC providers, 2010-11*

	Staffing	Non-staffing	Total
Planning	\$556	\$28	\$583
Development or modification of systems (e.g. IT systems) and processes	\$372	\$45	\$417
Development of information and other resources	\$242	\$26	\$269
Participant recruitment	\$167	\$10	\$177
Training and skills development	\$272	\$20	\$293
Other	\$366	\$169	\$536
<b>Total</b>	<b>\$1,976</b>	<b>\$300</b>	<b>\$2,275</b>

Based on data provided by 35 organisations, encompassing 441 packages allocated to those providers

Source: 1<sup>st</sup> CDC provider data collection (April-June 2011)

<sup>25</sup> Based on 35 organisations who submitted data for the April-June provider data collection. Refer to Appendix B for a breakdown of costs incurred.

Table 44: Estimated average set-up costs per CDRC package incurred by CDRC providers, 2010-11

	Staffing	Non-staffing	Total
Planning	\$246	\$5	\$251
Development or modification of systems (e.g. IT systems) and processes	\$71	\$20	\$91
Development of information and other resources	\$126	\$20	\$147
Participant recruitment	\$170	\$12	\$181
Training and skills development	\$82	\$50	\$132
Other	\$242	\$55	\$297
<b>Total</b>	<b>\$937</b>	<b>\$161</b>	<b>\$1,098</b>

Based on data provided by 13 organisations, encompassing 170 packages allocated to those providers.

Source: 1<sup>st</sup> CDRC provider data collection (April-June 2011)

It should be noted that these set-up costs are unlikely to be incurred if the initiative is rolled-out further. 'Planning' costs, for example, are unlikely to be incurred at the same level, given providers would have largely developed their approach to CDC and CDRC and are likely to be only refining their approach over time. However, there will reach a point where providers will need to invest in systems development to automate many of the processes that are being completed manually currently (such as preparation of monthly statements). This will represent additional one-off costs that are not reflected in the figures above.

## 9.3 Ongoing provider administration and care planning and management costs

### *Consumer-directed care*

#### *How fees were determined*

The majority of CDC providers did not differentiate between administration and care planning and management, and charged either an administration fee *or* a fee for care planning and management, but rarely both.

For CDC, there were a number of approaches to determining the administration fee charged:

- the standard 'overhead' charge levied on all divisions of the organisation (for large organisations). For example, if an organisation levied an overhead charge of 20 per cent of the budget for each division, then the administration charge for CDC packages was 20 per cent.
- a fee which was based on a 'reasonable' or 'acceptable' proportion of a package, typically without any reference to *actual* administrative costs.
- the fee suggested in the guidelines (15 per cent of a package).

Where a fee for care planning and management was charged (in addition to or instead of an administration charge), again it was typically based on:

- a predetermined amount per package based on an assumed number of hours of coordination per package. Some providers identified different amounts to be charged according to the degree to which a participant was self-managing their package (again based on an assumed number of hours).
- what was considered 'reasonable' or 'acceptable' to charge, typically without any reference to actual costs.
- actual time spent, based on a record of the number of hours that a coordinator spent on each participant.

#### *Fees charged – CDC*

The average administration charge per participant varied between care level – from \$1,610 per CDCL participant per annum (July-September figures) to \$3,573 per CDCHD participant. Care planning and management also varied – from \$1,323 per CDCL participant to \$5,815 per CDCHD participant per annum.

Administration and care planning and management charges together accounted for 22-23 per cent of a CDCL package subsidy, and 11-16 per cent of CDCH and CDCHD package subsidies.

This is illustrated in the table below.

*Table 45: Average administration and care planning and management charges per participant (annualised)*

	CDCL		CDCH		CDCHD	
	Apr-Jun	Jul-Sep	Apr-Jun	Jul-Sep	Apr-Jun	Jul-Sep
Administration	\$1,421	\$1,610	\$2,747	\$2,775	\$4,386	\$3,573
Care planning and management	\$1,612	\$1,323	\$4,133	\$2,253	\$3,237	\$2,242
<i>Combined</i>	<i>\$3,033</i>	<i>\$2,933</i>	<i>\$6,880</i>	<i>\$5,028</i>	<i>\$7,624</i>	<i>\$5,815</i>
<i>Proportion of package subsidy*</i>	<i>23%</i>	<i>22%</i>	<i>16%</i>	<i>11%</i>	<i>16%</i>	<i>12%</i>

\*note this is based on Commonwealth Government subsidy levels, rather than reported package expenditure

Source: 2<sup>nd</sup> CDC provider data collection (July-Sept 2011)

#### *Ongoing administration and management costs – CDC provider estimates*

As part of the evaluation, providers reported on their ongoing management, administration, care planning and support coordination and other expenditure relating to administering CDC and CDRC packages.

Providers were permitted to pass on these costs to participants' packages, though data analysis reinforces the claims made by many providers that they did not fully pass on these costs (and that to some extent they did not understand the actual costs they incurred).

The table below outlines the estimated ongoing management, administration, care planning and management and other expenditure per CDC package, compared with the average administration and care planning and management charges passed on to participants.

The table illustrates that:

- The estimated average cost for management and administration and participant selection was approximately \$4,023 per package. This compared to an average administration charge passed on to CDC participants of \$2,384 per package, indicating that providers were absorbing some of the ongoing management and administration costs.
- Including care planning and management, the estimated average cost per package incurred by providers was \$6,715 per package per annum, compared with the average combined administration and care planning and management charges passed on to CDC participants of \$4,053 per package.

*Table 46: Estimated average ongoing costs per CDC package incurred by CDC providers, per annum*

	Staffing	Non-staffing	Total
Management and administration	\$3,033	\$654	\$3,686
Participant selection	\$317	\$21	\$337
<b>Total (excl care planning and management)</b>	<b>\$3,349</b>	<b>\$674</b>	<b>\$4,023</b>
<i>Average administration charge – CDC participants</i>			\$2,384
Care planning and management	\$2,565	\$127	\$2,692
<b>Total</b>	<b>\$5,914</b>	<b>\$802</b>	<b>\$6,715</b>
<i>Average administration and care planning and management charges– CDC participants</i>			\$4,053

Source: 2<sup>nd</sup> CDC provider data collection (July-Sept 2011)

It should be noted that these costs were being incurred during the initial 6-12 month period when the initiative was being implemented. It is not clear whether these costs would continue to be incurred as providers become more familiar and comfortable with the CDC model and refine their own approach, and as participants take on more of a self-management role.

#### *Additional time spent on initiation, planning and coordination – CDC provider estimates*

The tables below illustrate the amount of time spent by providers on initiation (providing information to potential participants), undertaking care planning with participants, coordinating packages, and undertaking regular reviews.

For CDC, it is estimated that providers spent between 2.4 and 2.8 hours per potential participant providing them with information about the initiative and explaining what the initiative was about, and seeking their agreement to participate. This was largely a one-off cost at the commencement of the initiative (and will be incurred whenever providers were allocated additional CDC packages), and represents additional time associated with CDC that would not have been incurred for standard packaged care packages.

The average amount of time spent on planning with participants increased as the care level increased, and is higher for CDC compared to standard packaged care. Providers were spending between 0.8 additional hours (CDCL) and 1.5 additional hours (CDCHD) on planning for CDC packages compared with standard packaged care packages. Again, this was largely a one-off cost incurred when participants commenced on a package.

The average amount of time spent on managing and coordinating a package per week also increased as the care level increased, and was also higher for CDC packages compared with standard packaged care. Providers were spending between 0.4 additional hours per week (CDCL) and 0.6 additional hours (CDCH) on managing and coordinating CDC packages compared with standard packaged care packages. This translates to:

- approximately 19 additional hours per year managing and coordinating a CDCL package, or approximately \$1,000 in additional costs per CDCL package
- approximately 32 additional hours per year managing and coordinating a CDCH package, or approximately \$1,600 in additional cost per CDCH package
- approximately 27 additional hours per year managing and coordinating a CDCHD package, or approximately \$1,350 in additional cost per CDCHD package.

Table 47: Time (hours) spent on initiation, planning and coordination - CDC

	CDCL	CACP	CDCH	EACH	CDCHD	EACHD
Time spent providing information to potential CDC participants – per participant (hours) <i>one-off</i>	2.4	...	2.5	...	2.8	...
Time spent undertaking care planning – per participant (hours) <i>one-off</i>	2.9	2.1	3.9	2.5	4.2	2.7
Time spent managing and coordinating package– per participant per week (hours)	1.4	1.0	2.4	1.8	2.6	2.1
Time spent conducting formal review – per participant per review undertaken (hours) <i>every 3-6 months</i>	1.3	1.1	1.9	1.6	2.0	1.6

Source: 2<sup>nd</sup> CDC provider data collection (July-Sept 2011)

## Consumer-directed respite care

### How fees were determined

For CDRC, providers received a separate allocation for administration (\$4,200 per package), and did not charge an additional administrative fee.

CDRC providers also charged for case management and coordination, and used the range of approaches used by CDC providers (discussed above) to determine this charge, including:

- a predetermined amount per package based on an assumed number of hours of coordination per package
- what was considered ‘reasonable’ or ‘acceptable’ to charge
- actual time spent, based on a record of the number of hours that a coordinator spent on each participant.

### *Fees charged*

As noted in Table 7: *Breakdown on CDRC package expenditure*, the proportion of total package expenditure spent on case management and coordination was between 9 and 14 per cent.

However, not all CDRC participants were charged for case management and coordination, with providers meeting these costs from the \$2,000 administration allocation paid in addition to the package budget. For those participants that were charged a fee for case management and coordination, the average fee reported by CDRC providers was between \$237 and \$284 per participant per quarter in the two quarters for which data was collected. There was also considerable variation in fees charged for case management and coordination.

*Table 48: Case management and coordination fees charged – CDRC*

	Apr-June	July-Sept
No of participants charged a fee for case management and coordination	114	127
Prop. of participants charged a fee for case management and coordination	66%	65%
Range of fees charged	\$29-\$900	\$29-\$1470
Average fee per participant <sup>1</sup> – case management and coordination	\$284	\$237

<sup>1</sup> Average fees relate only to those participants who paid a fee for case management and coordination from their package. Participants who were not charged a fee were not included in the calculation.

Based on package expenditure reported by providers as part of the CDRC provider data collections. Excludes the \$2,000 administration allocation which does not form part of a package, and any fees associated with 'administration' reported by providers.

Source: 1<sup>st</sup> and 2<sup>nd</sup> CDRC provider data collection (April-June and July-Sept 2011)

### *Ongoing costs – CDRC provider estimates*

The table below outlines the estimated ongoing management, administration, case management and coordination and other expenditure per CDRC package, compared with the administration payment per CDRC package (\$2,000) paid in addition to CDRC package funding.

The table illustrates that the estimated average cost for management and administration and participant selection was approximately \$1,843 per package. This was slightly less than the \$2,000 administration payment per CDRC package, indicating that this payment was sufficient to cover CDRC providers' ongoing costs.

*Table 49: Estimated average ongoing costs per CDRC package incurred by CDRC providers, per annum*

	Staffing	Non-staffing	Total
Management and administration	\$1,197	\$251	\$1,448
Participant selection	\$374	\$21	\$395
Case management and coordination	\$852	\$29	\$881
<b>Total</b>	<b>\$2,423</b>	<b>\$301</b>	<b>\$2,724</b>
<b>Total (excl care planning and management)</b>	<b>\$1,571</b>	<b>\$272</b>	<b>\$1,843</b>
<i>Administration allocation per CDRC package</i>			\$2,000

Source: 2<sup>nd</sup> CDRC provider data collection (July-Sept 2011)

#### *Additional time spent on initiation, planning and coordination – CDRC provider estimates*

For CDRC, it is estimated that providers spent 2.5 hours per potential participant during the initiation phase – similar to the amount of time spent with potential CDC participants.

It is estimated that CDRC providers spend approximately 1.2 additional hours with each CDRC participant on planning compared with NRCP consumers (again, similar to CDC).

The average amount of time spent on managing and coordinating a CDRC package per week was also higher for CDRC packages compared with standard respite care. It is estimated that providers were spending approximately an additional 0.5 hours per week on managing and coordinating a CDRC package compared with managing and coordinating supports for NRCP consumers, or 26 additional hours per year.

*Table 50: Time spent (hours) on initiation, planning and coordination – CDRC*

	CDRC	NRCP
Time spent providing information to potential CDRC participants – per potential participant (hours) <i>one-off</i>	2.5	...
Time spent undertaking care planning– per participant (hours) <i>one-off</i>	3.0	1.8
Time spent managing and coordinating package– per participant per week (hours)	1.8	1.3
Time spent conducting formal review – per participant per review undertaken (every 3-6 months) (hours) <i>every 3-6 months</i>	2.3	1.1

Source: KPMG - 2<sup>nd</sup> CDC provider data collection

#### **Key points – Costs**

- Providers were incurring costs relating to the development and set-up of CDC and CDRC, and were meeting these costs themselves.
- While some set-up costs will not be incurred again by existing providers if the initiative is expanded, new providers can be expected to will incur these similar costs. Further, there are likely to be additional costs incurred for systems development as the number of packages reaches a critical mass and processes need to be automated.
- CDC providers were also incurring some ongoing costs which were not being met from package funds. Additional costs were largely due to the increased amount of time involved in administering and coordinating packages compared with standard care packages. In addition, CDC providers were largely determining their administration charges based on what they considered 'reasonable' rather than costs actually incurred. This was not the case for CDRC providers who were allocated a separate administrative amount per package.
- The extent to which these ongoing costs are likely to continue is unclear, though they may decline over time as providers become more familiar with the approach and participants take on a greater self-management role.

## 9.4 Considering the cost-effectiveness of the initiative

Given the evaluation was conducted at an early stage of the initiative's implementation, it was not possible to undertake a full cost-effectiveness analysis as part of the evaluation.<sup>26</sup> It is therefore not possible at this point in time to say whether consumer-directed care is cost-effective, or more or less cost-effective than standard packaged care and respite.

However, some high-level observations have been made relating to the cost-effectiveness of the initiative, based on data and qualitative evidence of outcomes collected as part of the evaluation. These observations are based on the following two questions:

1. Were CDC and CDRC participants able to access *more supports* for a given level of resources compared with standard packaged care and NRCP consumers?
2. Do CDC and CDRC participants realise *greater benefits or outcomes* for a given level of resources compared with standard packaged care and NRCP consumers?

### *More supports for a given level of resources?*

#### *Consumer-directed care*

It is very unlikely that most CDC participants were able to access *more* supports through a CDC package compared with a standard packaged care package. It is possible that some CDC participants were actually receiving *fewer* supports than they would under standard packaged care if providers were charging more for administration and care planning and management than under standard packages.

While the administration and care planning and management components of CDC packages were known (and were presented earlier in this chapter), there is no corresponding data for standard packaged care packages to compare to. However, as outlined above, there is evidence that the time involved in planning, administering, and coordinating a CDC package is higher for providers than a standard packaged care package. There is evidence that at least some of these additional costs were being passed on participants through administration charges and charges for care planning and management. While these additional costs were not substantial, it does mean that a slightly higher proportion of a CDC package is being used for administration and care planning and management, and a lesser proportion for services and supports, than under standard packaged care packages.

There is also some evidence that providing greater choice to participants was impacting on the amount that CDC providers were charging for administration and care planning and management, particularly when participants were selecting providers other than the CDC provider. There is evidence that some providers (though not all) were increasing the amounts charged for administration and care planning and management when they were required to

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<sup>26</sup> While a cost-effectiveness analysis was within the original scope of the evaluation, it became clear that a full cost-effectiveness analysis would not be able to be undertaken. As such, it was agreed with the Department, in consultation with the Evaluation Reference Group, that a 'cost assessment' would be undertaken instead of a cost-effectiveness analysis, and that guidance on undertaking would be provided on undertaking a full cost-effectiveness analysis once the initiative had been in operation for a longer period.

purchase or broker supports from other organisations to take into account the additional work involved. Again, for participants accessing a package through these providers, this increased the administration and care planning and management components of a package, and would leave fewer resources for services and supports.

On the other hand, as noted in chapter 5 (*Implementation and operation of the initiative*), some providers were implementing tiered or differential charging for administration and/or care planning and management, where the charges took account of the degree of self-management a participant or their carer was able to take on themselves. Where a participant was able to take on some or all of the coordination of their package, charges for administration and/or care planning and management were lower than if the provider were undertaking most or all of the coordination. Hence participants accessing a package through these providers, and self-managing their package to some degree, would potentially have had more resources for services and supports compared with standard packaged care. At this stage, however, there appears to have been relatively few participants who were fully self-managing their package.

It should be noted that there is no robust and consistent data available with which to compare levels of support accessed by CDC participants with levels of support accessed by standard packaged care participants. The only available measure for both groups was 'hours', though they were from two separate sources which were not comparable (CDC hours from the CDC provider data collection, and standard packaged care data from claims submitted by providers).<sup>27</sup> Further, 'hours' does not take into account the range of supports that were not measured in hours (such as equipment, home modification, transport), and can be skewed by very low cost supports which were measured in hours (such as on-call access).

#### *Consumer-directed respite care*

Unlike CDC, for CDRC there were no 'standard care packages' to compare to, hence it was not possible to determine whether a CDRC participant was able to access more supports for a given level of resources than carers accessing respite and other supports through the NRCP program. As for CDC, 'hours' was the only measure of level of support, and this is an imperfect measure given it can be skewed by low cost supports and does not include supports not measured in hours.

It is unclear whether CDRC participants were paying the full cost of services – particularly for Commonwealth-funded residential respite – or whether they were only paying the consumer fee from their package.<sup>28</sup> From the data available it appeared that participants were paying a very small fee for residential respite, indicating that they were not paying the full cost. Further, CDRC participants moving away from seemingly low-cost services such as residential respite to seemingly more expensive in-home and individualised supports will mean that CDRC participants were receiving fewer supports overall than NRCP consumers for a similar level of resources.

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<sup>27</sup> Actual comparisons made between average CDC hours per participant and average usual care hours per consumer revealed considerable differences, yet the level of resources available to each group were broadly similar.

<sup>28</sup> Data collected indicates that the fee charged to a CDRC package for Commonwealth-funded residential respite was \$2 per hour, compared with approximately \$35 per hour on average for in-home respite.

## ***Greater benefits or outcomes for a given level of resources?***

### *Evidence of benefit and outcome*

While there was some qualitative evidence of benefit and outcomes for CDC participants compared with standard packaged care consumers – particularly for those on higher care packages – there was no firm quantitative evidence of benefit or outcome available at this early stage of the initiative’s implementation.

As noted in chapter 6, during the period in which the evaluation data collection was undertaken, the majority of participants had been receiving their package for less than six months. While this may have been sufficient time for some participants to begin to experience some benefit or outcome from their package (and there was qualitative evidence from interviews and surveys that they were), other participants were still ‘getting used to’ their package and what they could do with it, and many providers were also still developing their own approach to CDC. This is likely to have impacted on the degree to which many participants experienced benefit or outcome from their package, and means that the full extent of benefit or outcome from the initiative is not able to be observed or measured at this stage.

For CDRC, there is considerable qualitative and survey evidence that CDRC participants have realised benefits and outcomes from receiving a CDRC package, and noticeable differences in levels of satisfaction between CDRC survey respondents and NRCP comparison group survey respondents – in a relatively short period. However, as noted in chapter 7, CDRC participants had an annual CDRC package allocation to spend over a period of six months or less, and it is likely that the benefits and outcomes realised were to some extent due to the level of resources available during this initial period.

### *Measures of outcome*

The evaluation used the ICECAP-O tool to derive a measure of wellbeing for the CDC and CDRC participant groups and standard care comparison groups. However, while the ICECAP-O tool measures wellbeing in older people, it is only a partial measure of outcome of the initiative, and there was no composite outcome measurement tool available which encompassed all potential outcomes.

The partial measure of outcome which was collected for each CDC and CDRC participant and consumer in the standard packaged care comparison group – the ICECAP-O wellbeing measure – showed *no statistically significant difference* between the CDC group and standard packaged care comparison group, and no statistically significant difference between the CDRC group and NRCP comparison group.<sup>29</sup> This indicates that *at this stage* there is no quantitative evidence that CDC or CDRC enhances wellbeing for participants.

Further, given the timing of the evaluation the ICECAP-O was administered at one point in time only. While comparisons were able to be made between the CDC and CDRC participant groups and standard care comparison groups, changes in wellbeing over time within each group could not be determined.

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<sup>29</sup> using the Mann-Whitney test for non-normally distributed data,  $p=0.05$

### *Undertaking a full cost-effectiveness analysis*

A full cost-effectiveness analysis was not conducted as part of the evaluation, given the length of time the initiative has been operating at the time the evaluation was conducted, and the lack of unequivocal *quantitative* evidence of benefit or outcome from the initiative compared with standard packaged care or respite care.

In addition, it is not clear whether the additional costs incurred by providers associated with implementing and administering the initiative and coordinating supports for participants will continue to be incurred, or whether costs will decline over time. While there was little evidence of participants self-managing their package to any significant extent at the time of the evaluation, as the initiative develops and participants' capacity to self-manage increases, it is possible that costs associated with administering packages and coordinating supports will decline.

Undertaking additional data collection and a full cost-effectiveness analysis should be considered as part of any future evaluation. This should occur once the initiative has been in operation for a longer period (at least two years), that is, when participants have had sufficient time to realise benefits or outcomes from participating in the initiative and the costs of the initiative have stabilised and are better understood. A cost-effectiveness analysis should encompass:

- a single measure of wellbeing or quality of life (for example, using a validated outcome measurement tool appropriate for older people such as the ICECAP-O). Ideally, the tool used should allow for quality-adjusted life years (QALYs) or disability-adjusted life years (DALYs) to be calculated. Further, the tool should be commonly used in the health and aged care sectors so that outcomes can be compared across programs or interventions.
- measurement of changes in wellbeing or quality of life for participants over time. This will require collection of data at different points in time – for example, at a baseline (for example, when participants commence a package, or a single point in time for all participants), and then periodically (for example, every three or six months over a defined period).
- collection of wellbeing or quality of life data from standard packaged care and respite comparison groups. This will ensure that any changes in wellbeing or quality of life attributable to the initiative can be isolated from changes attributable to receiving community aged care or respite care.
- the full costs of the initiative, including both set-up costs and ongoing costs, relative to the full costs of standard packaged and respite care. It is important that data is collected once the initiative has been in operation for a reasonable period (at least two years), that is, when costs have been fully realised and have stabilised.

## **9.5 Considering the financial sustainability of the initiative**

Again, it is too early to say whether the initiative is financially sustainable, given the ongoing costs of the initiative are not fully understood and are likely to change as the initiative continues. Provider costs are likely to stabilise and may even decline as they become more familiar with the initiative and more efficient in administering packages. Costs may also decline over time if more participants take on a greater self-management role.

There is evidence, however, that currently providers are bearing some of the additional cost of CDC and CDRC – in particular the costs of development and set-up, including systems development and changes and some of the ongoing costs of administering CDC (though not CDRC) packages. In the *short term*, if the number of CDC and CDRC packages were to increase (and costs do not decline), there may be a risk that providers will not be willing to continue to absorb this cost themselves, and may not be willing to take on more packages.

#### *Investment in systems and staff development*

As package numbers increase, there will reach a point when providers will need to invest substantial resources in systems development and changes to support CDC and CDRC – including changes to finance and client management systems and the interface between these systems – to support the operation of CDC and CDRC. For the first round of packages providers made some internal systems changes, though stated that they completed a number of tasks manually (for example, producing monthly participant statements) and relied on additional administrative support to complete other tasks (for example, matching client management records with finance records, or entering data multiple times into different systems). It is likely to be costly and inefficient for providers to continue to do this as package numbers increase, and without some investment in systems development, some providers may be unwilling to take on more CDC or CDRC packages. A lack of investment may also undermine key aspects of the CDC and CDRC models – such as transparency (for example, of budgets and package expenditure), and informed choice.

Further, during the first round providers did not invest heavily in training and development of their staff, and instead focussed their efforts on developing the skills of one or two coordinators who managed the CDC and CDRC packages allocated to the organisation. As the number of packages increase, there will be a need to undertake more staff training and skills development, including for a greater number of coordinators and potentially for direct care staff and the community care sector more broadly. Again, this represents an additional cost which providers are unlikely to be able or willing to meet, and a lack of investment in staff development and training is likely to undermine the effectiveness of the consumer-directed care approach.

If the initiative is to expand, the Department should consider investment in provider systems development and training to support the operation of CDC and CDRC.

#### *Ongoing financial support in the short-term*

Based on available data and discussions with providers, it appears that some providers were not passing on the full cost of administration and care planning and management to participants during the period of the evaluation (the first round of package rollout) – for CDC in particular – and were bearing some of the additional ongoing cost themselves. This is unlikely to be sustainable as CDC package numbers increase, and may result in a number of possible scenarios:

- Providers meet the additional administrative and care planning and coordination costs from package subsidies, reducing the amount of resources for direct supports for CDC participants
- Providers are less willing to take on additional CDC packages
- Key features of the CDC model are undermined, and the difference between CDC and standard packaged care becomes less distinct.

If the initiative were to continue to expand, the Department could consider increasing subsidy levels or making an additional administration payment to providers in addition to the subsidies paid – at least in the short-term – to take account of additional administrative and care planning and management costs incurred. This could be reviewed once ongoing costs are better understood and have stabilised.

**Key points – Cost-effectiveness and financial sustainability**

- It is too early to say whether consumer-directed care is cost effective, or more or less cost-effective than standard packaged care and respite. Undertaking a full cost-effectiveness analysis should be considered once the initiative has been operating for a longer period – when outcomes from the initiative are clearer and are able to be quantified more precisely, and when costs of the initiative have been fully realised and have stabilised.
- It is also too early to say whether the initiative is financially sustainable, given the ongoing costs of the initiative are not fully understood and are likely to change as the initiative continues. Provider costs may stabilise and may even decline as they become more familiar with the initiative and more efficient in administering packages. Costs may also decline over time if more participants take on more of a self-management role.
- If the initiative is to roll-out further, without additional financial support for set-up costs – specifically for systems development – there is a potential risk that key aspects of the initiative will be undermined.

## 10 Key findings

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This chapter summarises the key findings from the evaluation. The findings are organised around the evaluation themes.

### 10.1 Implementation and operation

#### *Program implementation*

**Key finding:** The initiative was implemented in a relatively short period of time, and providers would have appreciated more time to roll-out their CDC and CDRC packages, and more proactive guidance and support from the Department.

The initiative was implemented over a relatively short period of time, and the length of time between providers being informed that they had secured CDC or CDRC packages and rolling-out packages to participants was very short. As a result providers had little time to develop their approach to CDC and CDRC and to select participants.

Many providers indicated that they would have preferred more *proactive* support from the Department during the implementation, in addition to the helpdesk and frequently asked questions that the Department published. Providers suggested that some initial training or face-to-face briefings by the Department would have been useful, as well as more regular information exchange and discussion with other providers and the Department. In addition, providers would have preferred earlier provision of operating manuals.

Some providers appreciated the flexibility of the operating guidelines during the pilot period, but also would have liked clarification about a number of specific program issues.

**Key finding:** There were variations and inconsistencies in the way CDC in particular was implemented across different providers, and variations in the degree to which CDC was different from standard packaged care.

Variations were particularly evident in planning processes, in providers' degree of flexibility around the range and choice of services offered to participants, and in providers' openness to innovative or non-traditional services.

The degree to which providers were already flexible and person-centred in their approach influenced the degree of change that was needed for them to implement CDC. Those that were less flexible or person-centred, and/or that had less experience of consumer direction and person-centred approaches, appeared to face greater challenges in operationalising a form of CDC which was different from standard packaged care.

### ***Participant selection and planning***

**Key finding:** There was a higher level of interest in CDCH and CDCHD packages compared with CDCL.

Providers used a mix of approaches to selecting CDC participants, with some targeting existing packaged care clients and others new clients. Generally, there was more interest in (and demand for) higher care level packages.

In selecting participants, providers commonly targeted those with a carer or a family member actively involved in the older person's life (for CDCH and CDCHD). For low care participants, providers looked to people who they thought had sufficient capacity and who might have an interest in self-managing their package.

**Key finding:** There was a considerable level of interest in CDRC, with very few carers approached declining to participate.

CDRC providers tended to target potential participants who were already known to them, and who were considered a 'priority' (such as carers under stress or who had little or no access to formal supports), and who had the 'capacity' to participate in CDRC. A number of providers targeted younger carers who they considered were more appropriate for CDRC than older carers.

Several providers experienced considerable demand for CDRC packages from self-referring clients once the program became known.

**Key finding:** CDC and CDRC assessment and planning processes were either *goal-based* or *menu-based*.

Goal-based planning focussed on identifying the goals, desires and objectives of the participant and carer, and then looking to identify possible care and support options. Menu-based planning focussed on the ACAT needs assessment and provision of a list of available supports, providers and price list to the participant or carer.

Goal-based planning tended to be used with CDRC participants, for CDCH and CDCHD participants, and by providers who were more 'person-centred' in their approach to CDC and CDRC.

### ***Delivery and coordination***

**Key finding:** There were different models for delivery and coordination of CDC and CDRC. Those models that involved a progressive increase in consumer control appear to be the best suited for enabling a consumer-directed approach.

There were different models for delivery and coordination of CDC and CDRC. The predominant model used offered participants 'enhanced choices', with providers being responsible for coordinating and managing packages. Other models based on a progressive increase in consumer control and self-management, with structured variations in the level of support coordination and management undertaken by providers, appeared to be the most transparent and flexible approaches.

**Key finding:** Few participants fully self-managed their package to the extent that they were able to under the initiative.

Most participants were able to manage their package to some degree, at least to the level of making simple, day-to-day bookings and scheduling changes, maintaining timesheets, and managing problems such as support workers being late. However, few participants took on a substantial self-management role – either because they were not given that option by their provider, had no interest in self-managing their package and their support arrangements, or did not feel that they were able to.

## 10.2 Impact of CDC in participants and their carers

### *Extent to which CDC was person-centred and increased choice and control*

**Key finding:** CDCH and CDCHD participants and their carers were more interested and actively involved in planning and decision-making than CDCL participants.

CDCL participants were less interested in the planning aspects of CDC than CDCH and CDCHD participants (and their carers), particularly if they had transferred from a CACP and were satisfied with their current support arrangements. The majority of new CDCL participants were focussed on the supports that they could access – similar to new standard package recipients. This was due, in part, to the relatively limited CDCL package budget and the low level of supports available under a CDCL package.

CDCH and CDCHD participants, and specifically their carers, appeared to be more actively involved in planning and decision-making. Some participants and carers (usually younger carers) with prior experience of community care had clear ideas about what they wanted in terms of supports, and what they wanted to be 'different' with their CDC package – largely driven by dissatisfaction with their previous package.

**Key finding:** Participants chose the similar *types* of supports as those available under standard packaged care, and exercised choice and control over *how* the services were delivered (mostly around flexible service delivery and continuity of support workers).

Participants exercised choice and control over how the services were delivered, including choice of support worker, and being flexible in delivery days/times and tasks undertaken by support workers.

Participants generally used their package for 'core services', though in many cases also used some of their package funds for innovative and non-traditional supports. Provider attitudes to requests for services or other supports that were different from the 'usual menu' of services varied, however. Differences were driven by the variable understanding of and commitment to the initiative, and in some cases the variable commitment to a consumer-directed care approach.

### ***Extent to which CDC enhanced community-based care***

**Key finding:** Even after a short period of operation, CDC appeared to have a positive impact on participants' level of satisfaction with various aspects of their life, particularly for CDCH participants.

Participants reported increased satisfaction with their ability to participate in social and community activities, their ability to visit family and friends, the quality of their home life and close relationships, and their health and wellbeing.

Satisfaction was generally higher for CDCH participants than for CDCL, indicating that there is potentially more benefit for people with higher levels of need (and receiving more sizeable packages). Key enablers to these higher levels of satisfaction were the degree of flexibility and control participants had over their support arrangements.

Satisfaction was also generally higher for CDC participants who had prior experience of packaged care compared with those participants with no prior experience of packaged care, indicating that CDC represents an improvement over standard packaged care for many participants.

On the single measure of wellbeing, however, there was no statistically significant difference between the CDC participant group and the standard packaged care comparison group.

**Key finding:** For CDC, there can be a conflict between the level of consumer choice to expend their funds as they wish, and a provider's responsibility and duty of care to ensure they receive supports they need.

Several CDC providers had concerns about balancing the consumer choice element of CDC with the provider's duty of care. Several providers gave examples of requests by participants or carers for use of CDC funds that they had refused because they considered that the request would compromise the participant's care (for example, reducing the amount of personal care or clinical care a participant could use). Other providers were also concerned by participants choosing to build up a sizeable contingency fund by foregoing some regular supports. While providers discussed and negotiated alternatives with participants, it highlighted one of the key tensions in the CDC model.

## **10.3 Impact of CDRC on participants and the people they cared for**

### ***Extent to which CDRC was person-centred and increased choice and control***

**Key finding:** Overall there was a high degree of participant satisfaction with the CDRC approach and model.

There were considerable benefits for carers from being able to plan supports in advance, and from simply being involved in the planning process. For many carers, they felt that they were being recognised and valued as carers – often for the first time.

CDRC allowed carers to focus on themselves, rather than the person they cared for. Most were actively involved in planning, though for some it took a while to determine what they wanted to use their package for.

Some carers involved the people they cared for in planning discussions, though generally they were not *actively* involved in planning – the focus of planning was very much ‘carer-centred’.

**Key finding:** The relationship with the coordinator was particularly important and valued by participants.

The strength of this relationship (and the effectiveness of the coordinator’s skills) seemed important for clients in building their capacity to self-identify needs and goals, building their capacity to self-manage, and receiving emotional support and advice on a wide range of issues related to their caring.

**Key finding:** CDRC provided more choice of supports and more control and influence over the supports carers received than NRCP and other community care programs that carers had experienced.

In particular, participants tended to choose in-home and flexible supports which enabled them not only to ‘take a break’ but also to do the things they wanted to do, including social activities and spending more time with their own family. Only a small proportion of participants chose to use residential respite.

Many participants also used part of the package funding for ‘non-traditional’ supports, goods and services such as holidays, gym memberships, television subscriptions, continence products, and petrol.

### ***Extent to which CDRC enhanced community-based care***

**Key finding:** Even after a short period of operation, CDRC had a considerable positive impact on carers.

Many participants felt that their capacity to continue in their caring had increased since commencing on the package, and for many having a package gave them a chance to put energy back into their caring role.

CDRC also had a positive impact in terms of carers’ level of satisfaction with different aspects of their life - including their ability to participate in social and community activities, their ability to visit family and friends, the quality of their home life and close relationships, and their health and wellbeing.

However, using a validated measure of wellbeing, there was no statistically significant difference between the CDRC participant group and carers accessing supports through NRCP.

It also needs to be noted that during the period of the evaluation participants had access to a full annual package amount (\$4,200) – to be spent in six months or less – and participants were able to access a greater level of support than they would in an annual period. This is likely to have increased the scale of benefits experienced by CDRC participants.

## 10.4 Considerations for special needs groups

*Key finding:* There were few differences in experiences or levels of satisfaction between special needs groups, though the suitability of the current CDC and CDRC models for Aboriginal and Torres Strait Islander people and people who are homeless or at risk of homelessness is unclear.

Generally, there were no specific differences between participants from different special needs groups and those who did not identify as belonging to a special needs group. There were, however, elements of the CDC and CDRC approach that were important for participants from culturally and linguistically diverse backgrounds and carers of people living with dementia, such as the choice of support worker and the flexibility provided by CDC and CDRC.

There was a low representation of Aboriginal and Torres Strait Islander people in the CDC and CDRC participant groups. It is unclear whether the CDC and CDRC models are appropriate for Aboriginal and Torres Strait Islander people, and in particular the focus on the individual rather than the family or community.

For CDC participants who were homeless or at risk of homelessness, there was a greater need for more intensive care planning and management, though little interest in the 'consumer-directed' aspects of the CDC model.

## 10.5 Impact of CDC/CDRC on provider 'culture' and the broader service system

*Key finding:* CDC providers differed in the extent to which they considered that participating in the CDC pilot had changed their 'culture'.

Some providers had started to change their broader approach to standard packaged care by being more transparent about services and costs, trying a different approach to planning, and considering the use of individual budgets with some clients. However, this was not widespread.

## 10.6 Cost-assessment and cost-effectiveness

*Key finding:* There were set-up costs and some ongoing costs that providers were funding themselves.

Providers were incurring costs relating to the development and set-up of CDC and CDRC, and meeting these costs themselves. For the first round of CDC and CDRC packages, these costs are estimated to have been \$1 million for CDC and \$0.2 million for CDRC, or approximately \$2,000 per package. Some set-up costs will not be incurred again by existing providers if the initiative is expanded, though new providers will incur some costs. Further, there are likely to be additional costs incurred by providers for systems development as the number of packages reaches a critical mass and processes need to be automated. This investment will need to be funded by the Department.

Providers were also incurring some ongoing costs which were not being met from package funds. The extent to which these will continue is unclear, though may decline over time as providers become more familiar with the approach and participants take on a greater self-management role.

*Key finding:* The cost-effectiveness of the initiative is unclear.

Given the timing of the evaluation it was not possible to undertake a cost-effectiveness analysis. It is therefore not possible at this point in time to say whether consumer-directed care is more or less cost-effective than standard packaged care and respite. There are early indications that the benefits realised by CDRC participants and by CDCH and CDCHD participants are greater than for NRCP and standard packaged care, and that in terms of benefits-per-dollar invested, CDRC, CDCH and CDCHD could be relatively cost-effective. It is not as clear for CDCL.

## 11 Lessons learnt and strategies for consideration

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This chapter identifies the key lessons learnt from the implementation and operation of the initiative to date, and strategies for consideration to inform any future roll-out of consumer-directed care and consumer-directed respite care.

### *Providers needed more time to operationalise CDC and CDRC and to develop their approach*

Developing and implementing CDC and CDRC within an organisation takes time and planning. Community aged care providers and CRCCs varied significantly in the extent to which they were already person-centred and genuinely understood the consumer-directed approaches. The degree of change for some providers in implementing CDC or CDRC was substantial.

Should CDC and CDRC be rolled-out further, there should be a longer period of time to allow providers to better understand consumer-direction and to develop their approach, undertake skills development and training for staff, and make the necessary changes to systems and processes to support the operation of CDC and CDRC. This will be particularly applicable to providers who currently do not have any CDC or CDRC packages currently.

### *Providers needed support to build their capacity to be consumer-directed*

It was clear that providers varied in their implementation of CDC (and to a lesser extent CDRC). The degree of difference between CDC and standard care packages also varied, with some providers taking an approach which was very similar to standard packaged care, and others taking a considerably different, more person-centred approach, with the majority of providers somewhere between the two extremes.

CDC represented a fundamental shift in approach and thinking for many providers, and providers would have benefited from more guidance and support in the implementation of CDC.

A more proactive approach to building providers' capacity to be consumer-directed should be considered – targeting both existing CDC providers and new CDC providers. This guidance and support could be delivered in variety of ways, though should utilise experiences of providers to date (and learning from each other), and promote 'good practice' evident in the Australian experience or from other jurisdictions or sectors. Providers found that the State/Territory-based CDC provider forums that have been established by aged care peak bodies were useful in sharing knowledge and enhancing their understanding of CDC, and these forums could be utilised further and potentially enhanced or expanded.

Universities and Training and Further Education (TAFE) institutions could also contribute to embedding consumer-directed practices and a consumer-directed culture in the service system by enhancing the focus on consumer-directed care theory and practices in curricula for health professional qualifications and certificate courses for direct care workers. As a first step, aged care peak bodies could work together to advocate for these curriculum enhancements.

Further, at this stage the Department should consider maintaining the separation between CDC packages and standard packaged care – at least until such time as providers have had time to 'bed down' their approaches to CDC. Over time, it is likely that providers will modify their approaches to standard packaged care, and there is evidence that this was already occurring.

However, by removing the distinction between CDC and standard packaged care, there is a risk that CDC may not be embedded as a different approach to standard packaged care.

*Providers were very careful about making decisions which would be contrary to the guidelines*

The Department's approach was to give providers broad scope to operationalise CDC and CDRC within clear boundaries. However, a number of providers were either uncomfortable or not used to this approach (for example, because of their degree of risk aversion), and wanted more specific guidance and direction. Further, the guidelines did not necessarily convey this message. Some providers were, however, more comfortable with the broad scope of the initiative, were less risk averse and more willing to 'do things differently'.

As part of building provider capacity to be consumer-directed, the Department should also be clearer about providers' ability to make decisions regarding package operation themselves, building on their understanding of the approach and good practice.

The Department should also consider revising the guidelines so that they are less 'bureaucratic', and include more examples and case studies of good practice.

*CDC package amounts did not always reflect 'need'*

There were three subsidy levels for CDC (matching the subsidy levels for standard packaged care), and providers used these subsidy levels to determine package amounts. Similarly, CDRC packages amounts were set at the funding level provided (\$4,200).

It is noted that there is scope in the guidelines for providers to adjust the package amounts to reflect participant need, though providers were largely committed to being open and transparent about the funding and subsidy levels. At the very least the ability for providers to adjust the package amounts needs to be reiterated.

The Department could also consider providing a greater level of differentiation between the CDCL and CDCH *subsidies* provided (where the gap currently is more than \$30,000 per annum), and introducing at least two levels of funding for CDRC (for example, low and high support packages). It is recognised that for CDC this is currently not possible in the current aged care environment, though it is possible for CDRC.

*The balance between the number of CDCH/CDCHD packages and CDCL packages did not reflect demand, and there is more scope for CDCH and CDCHD participants and their carers to realise benefits from CDC than CDCL participants*

There was a high level of demand for CDCH and CDCHD packages, though there were relatively few CDCH and CDCHD packages allocated in the first round of the initiative. Conversely, there was a lower level of demand for CDCL packages, though a significant number. In addition, the evaluation revealed that, at this stage, the level of satisfaction with and benefits from CDCH and CDCHD packages were greater than for CDCL.

Should additional CDC packages be rolled-out, the Department should focus more on CDCH and CDCHD packages and less on CDCL packages.

*There were considerable benefits from using an individualised, package-based approach to support carers*

A package approach to supporting carers was a relatively new approach in Australia, and the demand for and benefits realised from CDRC were considerable.

The Department should consider wider roll-out of CDRC packages in their current form. This could be achieved through additional funding, or by converting existing NRCP funding to CDRC packages.

*There were demands from some CDC participants for more choice and control than was possible*

Some participants, and in particular (younger) carers of some participants, were dissatisfied with limitations on choice and control – including choice of supports, choice of CDC provider, and their ability to completely self-manage their package. While some of these limitations were imposed by providers, the CDC approach operates within the existing aged care regulatory environment which means that:

- CDC and CDRC packages are not portable (limiting participants' choice of CDC or CDRC provider)
- accountability for packages lies with providers rather than with participants (which limits participants' ability to completely self-manage their package).

It is recognised that the Department's options to allow for choice of CDC and CDRC provider is limited; this should be considered if the aged care regulatory environment changes in the future.

Similarly, removing some of the restrictions on participants completely self-managing their package could also be considered, including options for 'cashing out' packages. These options were discussed in the final report of the Productivity Commission Inquiry into aged care, *Caring for Older Australians*, and while recognising some of the risks of 'cashing out', the report specifically recommended a 'cashing out' option for respite supports (Productivity Commission, 2011b).

*There is potential for greater benefits to be realised by focussing more on building participants' capacity for self-management*

There was some evidence of providers working with participants to take on more of a self-management role, though the majority of participants relied on the provider to coordinate and manage their package and support arrangements. In most cases, providers did not encourage people to take on more responsibility for their package themselves, nor assist them to build their capacity, and some providers were uncomfortable with allowing participants to self-manage their package to any significant extent.

There is potential for greater benefits to be realised by focussing more on building participants' capacity for self-direction, and the Department should consider developing specific guidance and training for providers on how to build participants' capacity and encourage participants to take on more of a self-management role.

*There were set-up costs and some ongoing costs which may not have been expected, and which providers were funding themselves*

Providers reported that they were bearing some of the cost of the initiative themselves, including set-up costs and some ongoing administrative and management costs. Providers are unlikely to continue to do this.

At a minimum, the Department should consider providing some additional support to providers for set-up and development costs, and in particular for investment in systems and staff development and training to support the operation of the initiative. The Department should also investigate further the systems requirements to support CDC and CDRC and the potential to develop standard software or systems for use by all CDC and CDRC providers.

*Additional data collection will allow the outcomes and cost-effectiveness of the initiative to be better assessed*

Given the timing of the evaluation and the length of time the initiative had been operating, participant outcomes may not have been fully realised. Hence the data collected may not fully reflect the potential outcomes of the initiative.

The Department should consider undertaking further data collection and a full cost-effectiveness analysis once the initiative has been operating for a longer period, that is, when outcomes from the initiative are clearer and are able to be quantified more precisely, and when costs of the initiative have been fully realised and have stabilised. This data collection and cost-effectiveness analysis should:

- utilise a single measure of wellbeing or quality of life (for example, using a validated outcome measurement tool appropriate for older people such as the ICECAP-O). Ideally, the tool used should allow for quality-adjusted life years (QALYs) or disability-adjusted life years (DALYs) to be calculated. Further, the tool should be commonly used in the health and aged care sectors so that outcomes can be compared across programs or interventions.
- measure changes in wellbeing or quality of life for participants over time. This will require collection of data at different points in time – for example, at a baseline (for example, when participants commence a package or a single point in time for all participants), and then periodically (for example, every three or six months over a defined period).
- collect data from standard packaged care and respite comparison groups. This will ensure that any changes in wellbeing or quality of life attributable to the initiative can be isolated from changes attributable to receiving community aged care or respite supports.
- collect data on the full costs of the initiative, including set-up costs and ongoing costs, relative to the full costs of standard packaged and respite care. It is important that the cost data is collected after the initiative has been in operation for a reasonable period, that is, when costs have been fully realised and have stabilised.



## Appendices

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Refer to separate attachments

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cutting through complexity

# Evaluation of the consumer-directed care initiative – Appendices

Department of Health and Ageing

January 2012





## Appendices

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No warranty of completeness, accuracy or reliability is given in relation to the statements and representations made by, and the information and documentation provided by, the management and personnel of the Department consulted as part of the process.

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## A. Consumer-directed approaches – a review of literature

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### *Introduction*

This appendix provides an overview of the key features of existing consumer-directed approaches in the community aged care and other community care sectors. The focus is on the perspectives and experiences of older consumers (care recipients and carers), and on the outcomes and risks of consumer-directed models considered to be comparable to the Australian CDC model and important for the evaluation of the Australian CDC initiative.

### *Definition and development of consumer-directed care*

#### *Definition of consumer-directed care*

Consumer-directed care (CDC) is both a philosophy and an orientation to service delivery where consumers, including care recipients and their carers, can choose and control the services they get, to the extent that they are capable and wish to do so (AACS 2010, Rees 2010). The main objective of CDC is to offer consumers more choice and control than they would have from traditional and agency directed programs (Tilly and Rees 2007, Howe 2003).

#### *Development of CDC approaches*

CDC is usually traced to the disability rights and self-determination movements in North America and the UK in the 1970s, which resulted in the establishment of independent living grant programs in the 1980s. Doty (2010) traces the origins of CDC even earlier, to 1950s Los Angeles, when a home care program for polio patients confined to iron lungs was devised as a more cost effective alternative to inpatient care (Doty, 2010). This highlights one of the recurrent themes in CDC theory: home-based, consumer-directed approaches to care provision not only empower and satisfy consumers and carers, but are also cost effective for funders. The home-based polio care program eventually grew into the California In-Home Supportive Services (IHSS) program, which today provides self-directed home care services for 30,000 low-income children and adults with a disability as well as older people requiring in-home support. It is the oldest and largest CDC program in the United States (Doty, 2010).

A similar confluence of a consumer self-determination agenda and government recognition of potential cost savings in supporting home based care is also evident in Howe's identification of the Commonwealth Domiciliary Nursing Care Benefit (predecessor to the current Carer Allowance) as the 'pioneer of consumer direction in Australia' (2003).

In Australia, CDC models are widely used in the disability support sector, with the oldest such scheme, in Western Australia, having commenced in 1998 (Fisher et al 2010, Laragy and Naughtin 2009). All states and territories now offer some form of CDC involving individual budgets for adults requiring community care, and are actively working to expand those schemes (Productivity Commission 2011).

#### *Types of CDC models*

Ottmann, Allen and Feldman (2009) classify CDC models into two types:

1. 'Cash-for-care' models – this involves providing cash or vouchers for consumers to purchase their own care instead of receiving agency-directed in-kind care. Most of the US and European models fall into this category.
2. 'Self-directed' models – this is a more holistic model allowing consumers to choose among a continuum of care ranging from traditional case management through to direct payment and cash options.

The Australian CDC initiative falls into the second category, albeit with some limitations in terms of the continuum of care options because there is no direct payment component.

In most international and Australian jurisdictions, CDC is an *optional alternative* to agency-directed care (as it is with the Australian CDC model). In jurisdictions where there is a choice of care model, agency-directed services remain the dominant and preferred model (Tilley 2000). Older people in particular appear to prefer agency-directed services (ibid).

However, it should be noted that the Australian CDC model is the first such model specifically designed for older people (other models were designed for younger people with disabilities, and later expanded to include older people). The Australian CDC model also does not include a direct payment option, and international literature suggests that the perceived burden and stress of directly managing a budget was one of the aspects that many older people disliked in CDC and accounted for their preference for agency-direction. Accordingly, whilst the bulk of evidence suggests that older people prefer agency-direction to self-direction, this may not be the case in the Australian context.

The Australian CDC initiative is unique in that it has been designed specifically for older people. The evaluation will therefore provide an important contribution to the evidence base on consumer-direction for older people.

### ***Key features of consumer-directed care models***

The literature indicates that CDC programs typically include person centred approaches to needs assessment and planning resulting in an individual care plan, may have some form of individual budget option (possibly including an indicative upfront allocation to purchase services agreed under the plan), and will always feature some degree of consumer choice and control over the types of supports they can access and the providers that deliver those services.

Whilst there are common features, the presence or prominence of these features varies significantly across models, and thus the degree to which consumers have choice and control over their supports, and the degree to which they are involved in support planning, design and delivery, also varies.

This has implications for the evaluation. In particular, the evaluation needs to consider the impacts of particular design features of the CDC initiative in terms of the degree of consumer involvement, choice and control that care recipients and carers have (relative to standard packaged care), as well as the impact of this level of consumer involvement, choice and control on outcomes achieved by participants.

Common features of consumer-directed care models are discussed below, with comparisons to the Australian CDC initiative for community aged care.

### *Consumers are actively involved in the planning of their supports*

Consumer-directed care necessarily involves more active involvement of the consumer in the planning and design of the supports they receive, and the development of a person-centred or individual plan which considers their needs and goals as an individual, as well as their family/carer and life circumstances. This person-centred approach to planning is a key feature of successful consumer-directed models, for example:

- In Victoria, self-directed planning is defined as one of the three main components to its self-directed support model. It considers individual lifestyle choices, aspirations and goals as well as their skills, capabilities and life-stage (DHS, 2008). An individual plan is used as the basis for determining how self-directed funding is spent.
- In the UK, adult social care services have been transformed over the past decade with the introduction of a personalised care agenda. A person-centred assessment and planning process is used to develop a personalised plan. More recently, there has been a move to greater *self*-assessment and planning by consumers, and refocussing service system resources on case management and support delivery (Department of Health 2009).

### *Consumers are provided with personal budgets or individual funding allocations*

Along with personalised planning, one of the key features of a consumer-directed care approach is individualised funding allocations or personal budgets over which consumers have some form of control. The degree to which consumers have control over their allocation or budget, and the limitations placed on how funds can be used, varies significantly across models. For example:

- In the Western Australian disability sector, all funding is now individualised (with the exception of some respite and therapy services which continue to be 'block-funded') (FaHCSIA, 2010). However, for some service types such as accommodation, consumers have a 'notional allocation' of funding which is allocated directly to the provider, but which is portable if they chose to access services from another provider. Consumer choice and control is relatively limited. On the other hand, under the Local Area Coordination program consumers can receive direct payments and have significantly more control over how they use these funds (and are supported to do this).
- In the UK social care system, provision of individual budgets for eligible consumers (including older people) who wish to use them is a fundamental component of the personalisation policy (Department of Health 2009). Consumers who elect to have a 'personal budget' can elect to receive a direct payment of funds which they can manage themselves (and purchase their own care and supports), have their personal budget held and managed for them by a third party, or their personal budget is co-managed.
- Direct payments to consumers for attendant care (personal care) services have been in place in Canada (Ontario, British Columbia, and Nova Scotia) for over a decade.

Most models have an option of direct payment to consumers in the form of cash or vouchers, or co-managed budgets where the consumer and a third party jointly manage a personal budget. Where funds are co-managed, a third party holds the funds but the consumer has significant control over expenditure. In some jurisdictions (such as the UK), personal budgets can be made up of both direct payments and co-managed funds. In some European jurisdictions, such as the Netherlands, there are requirements for independent audits of

expenditure to ensure direct payments are used to support care, whilst in other jurisdictions (Germany and Austria) there are few restrictions on how direct payments may be used and few if any audit requirements. In fact, in those jurisdictions, funds are often pooled with other household income by the care recipient and their family and is often not actually used to purchase care.

Whilst the Australian CDC initiative does not include direct payments, one of its features is co-managed funding allocations held by CDC providers and accountable to consumers. This co-management of funding is a key distinguishing feature of CDC compared with standard packaged care. The extent to which these allocations are in fact co-managed will be an important part of the evaluation, given this feature of the model will have implications for the degree of consumer choice and control over the care that they receive.

The literature suggests that older people are less willing to directly manage their budgets than younger people with a disability. It is notable that, in contrast to much of the international concern with individual budgets, the Australian discourse on CDC to date has focused on participative care planning, access to choice of services and providers, and increased consumer control over delivery to a far greater degree than on individual budgets and direct payments (AACS 2010, Rees 2010, Tilly and Rees 2007, Howe 2003).

#### *Consumers have choices over the supports they receive and the design of these supports*

Consumer choice can relate to two things: choice of services and choice of provider of services, and typically consumer-directed care models allow both. However, consumer-directed care models differ in the degree of choice that consumers have, and in particular the limits placed on consumer choice:

- At one end of the continuum of choice, consumers can receive direct payments and be relatively unrestricted in terms of the supports that they can purchase and the providers of these supports. As indicated above, in a number of European models consumers can receive cash payments to directly employ support workers, and in some cases employ family members, rather than use their allocation for specific service types from pre-approved providers.
- At the other end, consumers can only choose from a limited menu of services (which may be based on pre-defined 'service types') from pre-approved or accredited providers. This is evident in early consumer-directed models applied to specific disability service programs in Australia (for example, the Community Participation and Transition to Work programs for people with a disability leaving school in NSW). The Australian CDC initiative falls into this second category.

The literature shows that, regardless of the extent of choice permitted within the model, a critical enabler for any effective consumer-directed care program is support for informed decision-making by consumers and carers. At the most basic level consumers and carers need reliable and accurate information about the range of supports that are available to them and scope to influence and design the supports they receive, the range of providers of these supports and services, and the quality and suitability of these supports and services. Consumers may also need support and assistance to make choices – for example, through a facilitator, support planner, or care manager (Chenoweth 2009).

Examining the effectiveness of the Australian CDC initiative in facilitating informed decision-making will be an important focus for the evaluation, as will examination of any limitations placed on consumers in terms of the choices they can make, and the extent to which that choice is exercised, and the impact of those limitations on consumers' satisfaction with the level of choice and control they have over their care. In looking at both of these aspects, it will be important to examine the range of information and support that CDC participants have available to them to make choices.

*Summary comparison of CDC models: Key features and outcomes*

Table A1 below provides a comparative overview of the *key features* of several international CDC models that are available to older people. Table A2 provides a summary overview of *outcomes* associated with various Australian and international CDC models.<sup>1</sup>

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<sup>1</sup> It should be noted that the Australian models relate only to people with a disability, whereas the international models encompass both older people and people with a disability.

Table A1: Comparison of various CDC models – key feature and options

Jurisdiction	Program name	Program type	Budget options	Planning options	Delivery options
Australia	Consumer-directed care	Consumer-directed	Agency-managed funds	Consumer-directed, pre-agency-managed care planning	Consumer-directed pre-approved agency services
Austria	Long-term care insurance	Consumer-managed ('cash for care')	Direct payment	Consumer-managed care planning.	Funds can be used at consumer's discretion
Canada (British Columbia)	Choice in Supports for Independent Living (CSIL)	Consumer-managed ('cash for care')	Direct payment	Consumer-managed care planning (with agency/broker).	Employment of carers (including relatives)
France	Long-term care insurance	Consumer-directed	Direct payment Co-managed funds	Consumer-managed care planning.	Employment of carers (including relatives) and equipment purchase
Germany	Care allowance	Consumer-directed	Direct payment Co-managed funds Agency-managed funds	<i>Direct payment option:</i> Consumer-managed care planning. <i>Co-managed or agency-managed option:</i> Consumer-directed, pre-agency-managed care planning	<i>Direct payment option:</i> funds can be at consumer's discretion <i>Co-managed or agency-managed option:</i> consumer-directed pre-approved agency services
Netherlands	Personal budget	Consumer-managed ('cash for care')	Direct payment	Consumer-managed care planning.	Employment of carers (including relatives) and equipment purchase
Sweden	Self-managed care	Consumer-managed ('cash for care')	Direct payment	Consumer-managed care planning.	Employment of carers or purchase of agency services

Jurisdiction	Program name	Program type	Budget options	Planning options	Delivery options
United Kingdom (England)	Personal budget	Consumer-directed	Direct payment Co-managed funds Agency-managed funds	Self-assessment and planning (with broker/facilitator)	Purchase of agency services or employment of carers
United States (various states)	Participant-directed care (cash and counselling)	Consumer-managed ('cash for care')	Direct payment	Consumer-managed care planning (with agency/broker).	Purchase of agency services or employment of carers (including relatives)
United States (California)	In-Home Services (IHSS)	Supportive Consumer-managed ('cash for care')	Direct payment	Consumer-managed care planning (with agency/broker).	Purchase of agency services or employment of carers (including relatives)
United states (Washington State)	Home and Community-Based Services	Consumer-managed ('cash for care')	Direct Payment Co-managed funds	Consumer-managed care planning (with agency/broker).	Purchase of agency services or employment of carers (including relatives)
United States (Wisconsin)	Family Care Program	Consumer-directed	Agency-managed	Consumer-directed, pre-agency-managed care planning	Consumer-directed pre-approved agency services

Source: Information in this table has been primarily drawn from the following sources: Glendinning 2008, Hardy 2008, Kodner 2003, Lundsgaard 2005, Productivity Commission 2011, Tilly, Wiener and Evans Cuellar 2000. The literature indicates that CDC programs based on direct payment models are also operating in Israel, Japan, Korea, Luxembourg and Norway, but insufficient descriptive information was identified to include them in this summary.

*Table A2: Comparison of various CDC models – evaluated outcomes*

Jurisdiction	Evaluation details	Consumer outcomes	Carer outcomes	Cost effectiveness	Areas to improve
Australia (Victoria)	Direct payments trial (2007)	High satisfaction	-	-	-
	UCCO CDC trial (2009)	High satisfaction	Variable satisfaction (felt isolated over time)	-	Social inclusion of carers
Australia (WA)	LAC review (2003)	High satisfaction (but lower for CALD/ ATSI)	-	Cost effective compared to agency direction	Tailoring for CALD and Indigenous clients
Austria	LTC review (1998)	-	-	-	-
Canada	CSIL review (2008)	High satisfaction	High satisfaction	-	-
France	-	-	-	Cost effective compared to agency direction	-
Germany	(2008)	Higher satisfaction than for agency directed consumers Increased paid care hours	-	-	-
Netherlands	(1996, 1998)	Higher satisfaction than for agency directed consumers Quality of care equal to agency directed care	-	-	Use of fiscal agents to prevent abuse (not relevant to Australian CDC model)

Jurisdiction	Evaluation details	Consumer outcomes	Carer outcomes	Cost effectiveness	Areas to improve
United Kingdom (England)	Individual budgets pilot (2007)	Satisfaction higher than for agency directed consumers  Lower psychological wellbeing for older consumers	Positive impact on quality of life and social outcomes  Satisfaction with care planning a predictor of outcomes		Safeguarding and quality control of paid carers (not relevant to Australian CDC model)
United States	Cash and counselling demonstrations (2007)	Higher satisfaction than for agency directed consumers  Reduced unmet demand  Reduced nursing home use  Quality of care equal to agency directed care	Higher satisfaction than agency-directed carers		Use of fiscal agents to prevent abuse (not relevant to Australian CDC model)

Information in this table has been primarily drawn from the following sources: Arntz 2008, Dale and Brown 2006, Foster, Disability Services Commission 2003, Glendinning 2008, LDC 2007, Ottmann, Laragcy and Haddon 2009, Phillips 2003 and Tilly and Bectal 1999

## *Outcomes and risks of CDC*

The literature suggests many broad benefits for consumers and carers participating in CDC models: increased hours of paid care, increased consumer and carer satisfaction, improved health and wellbeing outcomes, reduced unmet needs, and potential for cost savings in comparison to agency-directed approaches.

Importantly, the extent to which these benefits are experienced by *older people* participating in CDC is highly variable (Laragy and Naughtin 2009, Ottmann 2009, Glendinning 2008, Lundsgaard 2005, Phillips 2003, Tilly 2000).

### *Outcomes for older people*

Studies of CDC models in Europe and North America consistently suggest overall positive impacts of CDC on the level of consumer satisfaction with the care they receive, level of consumer independence, wellbeing and quality of life, and perceived quality of care (Glendinning 2008, Wiener 2007, Tilly and Bectal 1999, Benjamin et al 1998), increased hours of paid care (Glendinning 2008, Foster 2005), fewer unmet needs and adverse health events, reduced nursing home admissions (Carlson 2007), and less reliance on case management (Laragy and Naughtin 2009). Consumers who participate in CDC are generally at least as satisfied or more satisfied with their care outcomes (Ottmann, Allen and Feldman 2009).

However, almost without exception<sup>2</sup>, the positive impacts are lower for older people than for younger people using CDC programs. In some cases, older people experienced worse outcomes and greater anxiety directly related to managing an individual budget (Glendinning 2008). Australian consumer research has shown that many older people see CDC as burdensome rather than empowering (Carers Victoria 2010).

Where older people do choose to participate in CDC, they may prefer a 'mix and match' of agency-directed services with a small direct payment component for additional services (Nicholls 2007). The direct payment option is not a feature of the Australian CDC model, which instead features an individual budget coordinated through an agency. In the UK, many older people prefer this type of arrangement even where a full or partial direct payment option is available. Older people may choose to receive an individual budget with agency-direction because there is little scope to change the essential tasks they require assistance with anyway (and/or because they do not want the perceived burden of self-management), but they do appreciate the opportunity to change other elements, such as service times, to suit themselves (ibid).

In terms of implications of this for the Australian CDC evaluation, it is clear that more information is needed on the outcomes of CDC for older people and so the evaluation will contribute to this evidence base. It will be important to explore with participants their reasons for choosing to participate in CDC in the first place, the extent to which their expectations of CDC have been met, and any differences in outcomes between older people utilising CDC and the comparison group of older people accessing standard packaged care (recognising the length of time that the initiative has been in operation, and the particular design features of CDC which may impact on the achievement of outcomes).

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<sup>2</sup> In one US studies of direct payment style CDC model, older people were more satisfied than younger CDC participants (Wiener, Anderson and Khatutsky 2007), but the bulk of the literature – and in particular the findings from randomised control group evaluations of CDC models – find the opposite: that older people are less satisfied.

### *Carer outcomes*

Although there is little literature on the impact of CDC on carers (as opposed to care recipients), there is some evidence of potential positive impacts. CDC approaches can provide more opportunities for carer involvement in the planning and delivery of services, and can result in greater consideration of the carer's own needs (Arksey 2009). The UK randomised control trial found that carers' satisfaction with and level of involvement in the initial assessment and care planning process was a predictor of their overall satisfaction with CDC (ibid).

However, CDC may also have the potential for negative effects on carers if they feel less supported than they would in agency-directed services. There is some Australian evidence that participation in CDC may increase carers' feelings of isolation and lack of support over time (Ottmann, Laragy and Haddon 2009).

Carer experiences and outcomes will be a key consideration of the Australian CDC evaluation.

### *Cost effectiveness*

CDC is cited as a potentially more cost effective, financially sustainable model of care which can better respond to the pressures of an ageing population by supporting ageing in place and reducing inpatient and residential care, as well as meeting increasing consumer demand for more flexibility and control (Laragy and Naughtin 2009, Lundsgaard 2005). The potential cost savings are one of the main factors indicated by governments for expanding CDC (ibid).

European and US studies of CDC models have found CDC models to be more cost effective than agency-directed models where the CDC model is based on a direct payment system. This is because of the reduced labour costs associated with direct employment of support workers, particularly relatives, and reduced agency case management costs.

It is not clear whether individual budget models of CDC that involve shared or co-managed budgets – either alongside direct payments (such as the Victorian and UK models) or instead of direct payments (such as the Australian CDC model) are any more or less cost effective than traditional agency-directed models (Arntz 2008).

### *Risks associated with CDC*

The literature cites a number of risks and issues associated with CDC approaches. Some of these are particularly relevant to the Australian context, but many of the commonly-cited risks are not relevant to the Australian CDC model. For example, potential risks related to potential financial abuse of care recipients by carers and other family members, risks related to misuse of care funds, and risks related to compromised quality of care have been mitigated in the Australian model which does not provide for any direct payments, required budgets to be managed by an already approved provider, and only allows expenditure on service types already approved under existing packaged care programs.

The risks that may be relevant to the Australian CDC model and which will be considered in the evaluation are as follows:

- Ability to effect cultural change: Service sector cultural change and workforce training to support successful CDC implementation is one of the most consistently cited risks in the literature. Workforce considerations and cultural change (and in particular how different CDC is from standard packaged care) will be considered in the evaluation – particularly through the provider interviews, as well as the consumer and carer consultations.
- Consumer capacity: The capacity for frail older consumers and/or consumers with cognitive impairments is a common concern of CDC programs. All existing CDC programs allow for

involvement of carers or other representatives for those consumers that may want or require additional help. The Netherlands requires a surrogate decision-maker for all consumers with cognitive impairments. Most CDC programs involve a facilitator/care broker to assist consumers – indeed, this has been identified as a critical success factor for CDC programs (Chenoweth 2009). This can alleviate risks relating to consumer capacity.

- Accountability and transparency of individual budgets (to consumers and to funders/government): This is another issue frequently cited as a risk for CDC programs. It will be important in the evaluation to explore the extent to which consumers genuinely ‘co-manage’ their allocation and the extent to which they are aware of how it is being spent (transparency for consumers), as well as any unforeseen consequences of accountability requirements dictated by government (for example, whether they restricted choice for consumers or the way providers implemented CDC).

### ***Implications and considerations for the evaluation***

The literature review identified the following key points of relevance to the evaluation of the consumer-directed care initiative:

- Overall, consumers participating in international CDC programs tend to show greater levels of satisfaction with quality of care, fewer unmet needs, and better health and wellbeing outcomes than consumers in agency-directed programs. A key aspect of the evaluation will be testing this in the Australian context by comparing the satisfaction and quality of life outcomes for consumers in the CDC group to those in the standard packaged care group.
- Outcomes for older people participating in international CDC programs appear to be not as good as those for younger people with disability participating in the same programs. It is notable that none of these programs were specifically designed for older people. More evidence on the impact and outcomes of CDC for older people is required. The evaluation will contribute to this evidence base by looking at the impact and outcomes of older people participating in a CDC program that has been specifically designed for their cohort group.
- Given the unclear findings in the literature concerning the extent to which older people want to be involved in managing their budgets as part of a CDC program, another key area for exploration in evaluation will be whether participating consumers wanted more or less control of their allocations than was offered. This will assist in considerations for the future directions of the CDC initiative after the pilot period.
- The UK evaluations suggest that carer satisfaction with CDC is linked to satisfaction with initial care planning, and their level of involvement in those processes. Accordingly, overall carer satisfaction and the extent to which carers were satisfied with CDC planning and their involvement in CDC planning will be another key area of interest for the evaluation.
- There is some Australian evidence that, over time, carers participating in CDC may feel isolated or unsupported in comparison to those participating in agency-directed services. Whilst the evaluation period does not allow longitudinal measurement of carer experience and perception over time, this does again highlight carer satisfaction and experience as a key area of interest to the evaluation.
- A number of critical success factors for CDC relate to providers and their willingness to ‘allow’ consumers a more active role. These encompass providers’ techniques for recruiting participants, the adequacy of the information they provide to consumers and carers, the level of support they provide to consumers and carers, the extent to which they build capacity in participants to engage in CDC, the extent to which they build capacity in their staff to engage in and support CDC, and their overall acceptance of CDC. These factors have been shown to

influence CDC program success and outcomes in the US and UK evaluations, and will be relevant areas for consideration in the Australian CDC initiative.

- There is some evidence suggesting that CDC can reduce system costs by reducing case management and agency overheads. However, there is a 'back room' cost to administering and monitoring individual budgets which is not always evident in the literature. Assessment of any additional costs of CDC relative to standard packaged care will be a focus of the cost analysis component of the evaluation.

## B. CDC and CDRC participant and comparison group survey data

This appendix outlines responses from the CDC participant group and packaged care comparison group surveys, and the CDRC participant group and the NRCP comparison group survey.

The surveys sought participants' perspectives of the impact and benefits of CDC/CDRC compared with standard packaged care, as well as their experiences relating to the planning, budgeting and service delivery aspects of CDC/CDRC.

### B.1 Survey response rates

There was relatively high response rate to the surveys across all groups of approximately 39 per cent.<sup>3</sup> Response rates for each of the four groups – CDC and CDRC participants and the packaged care and NRCP comparison groups – were outlined in the table below.

*Table B1: Survey response rate*

Group	Sent*	Returned	Response rate
CDC participants	335	124	37%
Packaged care comparison group	335	126	38%
CDRC participants	172	92	53%
NRCP comparison group	172	55	32%
<b>Total</b>	<b>1014</b>	<b>397</b>	<b>39%</b>

\*This represents the approximate number of surveys sent by providers to participants and comparison group members, and is based on the number of people who had accessed a CDC or CDRC package during the April-June quarter.  
Data excludes those who did not sign the consent form accompanying the survey.

### B.2 Consumer-directed care and comparison group survey responses

#### *Respondent characteristics*

The tables below outline the characteristics of respondents to the CDC participant survey and the packaged care comparison group survey.

*Table B2: Respondent characteristics - CDC*

Characteristic	CDC	Comparison
<i>Age</i>		
Under 50	0%	0%
50-64	6%	1%
65-74	16%	23%
75-84	44%	37%
85+	33%	38%
Blank / No response	1%	1%

<sup>3</sup> The actual return rate is likely to be higher, given we understand that not all CDC and CDRC packages had been allocated to consumers or carers at the time the surveys were sent.

Characteristic	CDC	Comparison
<i>Gender</i>		
Male	39%	37%
Female	60%	62%
Multiple response	1%	0%
Blank / No response	1%	1%
<i>Current living arrangements</i>		
Live alone	41%	54%
Live with spouse /partner	40%	32%
Live with family	14%	10%
Other (please specify)	1%	2%
Multiple response	1%	0%
Blank / No response	3%	2%
<i>Carer status</i>		
Has a carer	56%	60%
Does not have a carer	39%	36%
Multiple response	1%	0%
Blank / No response	5%	5%
<i>Dementia status</i>		
Has dementia	23%	13%
Does not have dementia	76%	85%
Multiple response	0%	0%
Blank / No response	1%	2%
<i>Disability status</i>		
Has a disability	62%	63%
Does not have a disability	35%	31%
Multiple response	0%	0%
Blank / No response	3%	6%
<i>Pension status</i>		
Full Centrelink pension	54%	55%
Part Centrelink pension	15%	14%
Another type of pension	12%	14%
Do not receive a pension	11%	9%
Multiple response	6%	6%
Blank / No response	2%	2%

Characteristic	CDC	Comparison
<i>Special needs groups status</i>		
Aboriginal and / or Torres Strait Islander origin	1%	2%
Born in a non-English speaking country	18%	12%
Live in a rural or remote area	19%	15%
Veteran, a spouse / partner of a Veteran or a widow / widower of a Veteran	11%	17%
No permanent accommodation, and live in temporary accommodation	1%	1%
No permanent or conventional accommodation	1%	0%
Raised in an orphanage, out-of-home care or foster care (care-leaver)	3%	0%
None	46%	54%
<i>Do you have someone who does not live with you whom you can call on for assistance during a crisis?</i>		
Yes	84%	90%
No	15%	8%
Multiple response	0%	0%
Blank / No response	2%	2%

Table B3: Length of time receiving current package

Characteristic	CDC	Comparison
Less than 1 month	2%	1%
1 to 3 months	20%	8%
3 to 6 months	32%	10%
More than 6 months	42%	78%
Multiple response	1%	1%
Blank / No response	3%	2%

Table B4: Receiving any other community care services before commencing current aged care package

Characteristic	CDC	Comparison
Yes - a Community Aged Care Package (CACP)	40%	27%
Yes - Extended Aged Care at Home (EACH)	5%	2%
Yes - Extended Aged Care at Home, Dementia (EACHD)	2%	1%
Yes - other types of community care services	15%	25%
No, I did not receive any community care services before	22%	36%
Don't know / Not sure	8%	5%
Multiple response	4%	2%
Blank / No response	4%	3%

## Responses to survey questions

The tables below outline the responses to each survey question for the CDC participant group and the packaged care comparison group.

In most cases, the same question was asked in each survey, though there were some additional questions included in the CDC participant survey only.

Question / response	CDC	Comparison
<i>Table B5: Why did you choose to participate in the CDC initiative?</i>		
I wanted to have more choice of which services I used	35%	
I wanted to have more choice of providers	15%	
I wanted to have more control over my care planning	35%	
It was recommended by my care provider	69%	
I was not satisfied with my previous community care	6%	
<i>Table B6: I felt included in the process of planning my care services</i>		
Strongly disagree	0%	1%
Disagree	1%	1%
Neither agree nor disagree	4%	6%
Agree	51%	49%
Strongly agree	40%	37%
Don't know	0%	2%
Not applicable to me	1%	2%
Multiple response	1%	1%
Blank / No response	2%	2%
<i>Table B7: My needs and goals were taken into account in the process of planning my care and services</i>		
Strongly disagree	0%	0%
Disagree	1%	2%
Neither agree nor disagree	2%	3%
Agree	52%	52%
Strongly agree	43%	40%
Don't know	0%	1%
Not applicable to me	0%	1%
Multiple response	1%	1%
Blank / No response	2%	1%

Question / response	CDC	Comparison
<i>Table B8: I had enough information about the types of services that I could choose</i>		
Strongly disagree	0%	
Disagree	9%	
Neither agree nor disagree	3%	
Agree	56%	
Strongly agree	26%	
Don't know	1%	
Not applicable to me	1%	
Multiple response	2%	
Blank / No response	2%	
<i>Table B9: I had enough information about the service providers that I could choose to receive services from</i>		
Strongly disagree	1%	
Disagree	7%	
Neither agree nor disagree	7%	
Agree	60%	
Strongly agree	22%	
Don't know	0%	
Not applicable to me	1%	
Multiple response	0%	
Blank / No response	2%	
<i>Table B10: I had enough information about the costs of my care and services</i>		
Strongly disagree	1%	
Disagree	6%	
Neither agree nor disagree	6%	
Agree	59%	
Strongly agree	23%	
Don't know	2%	
Not applicable to me	1%	
Multiple response	1%	
Blank / No response	2%	

Question / response	CDC	Comparison
<i>Table B11: My planning provider helped me to make decisions regarding the types of services I could choose</i>		
Strongly disagree	1%	
Disagree	1%	
Neither agree nor disagree	2%	
Agree	60%	
Strongly agree	31%	
Don't know	1%	
Not applicable to me	1%	
Multiple response	1%	
Blank / No response	2%	
<i>Table B12: I was satisfied with the help I received from my planning provider</i>		
Strongly disagree	0%	
Disagree	2%	
Neither agree nor disagree	2%	
Agree	54%	
Strongly agree	37%	
Don't know	0%	
Not applicable to me	1%	
Multiple response	2%	
Blank / No response	2%	
<i>Table B13: I was satisfied with the range of services that I could choose</i>		
Strongly disagree	0%	1%
Disagree	5%	2%
Neither agree nor disagree	4%	4%
Agree	60%	53%
Strongly agree	27%	39%
Don't know	1%	0%
Not applicable to me	1%	0%
Multiple response	1%	1%
Blank / No response	2%	1%

Question / response	CDC	Comparison
<i>Table B14: I was satisfied with the range of different service providers that I could choose to receive my services from</i>		
Strongly disagree	1%	
Disagree	4%	
Neither agree nor disagree	13%	
Agree	54%	
Strongly agree	19%	
Don't know	0%	
Not applicable to me	6%	
Multiple response	0%	
Blank / No response	3%	
<i>Table B15: I received the services I wanted to receive</i>		
Strongly disagree	0%	1%
Disagree	4%	2%
Neither agree nor disagree	6%	6%
Agree	54%	53%
Strongly agree	33%	37%
Don't know	0%	0%
Not applicable to me	0%	0%
Multiple response	0%	1%
Blank / No response	3%	1%
<i>Table B16: Overall, I felt confident in making decisions about my care package and providers</i>		
Strongly disagree	0%	
Disagree	2%	
Neither agree nor disagree	4%	
Agree	54%	
Strongly agree	35%	
Don't know	0%	
Not applicable to me	0%	
Multiple response	0%	
Blank / No response	5%	

Question / response	CDC	Comparison
<i>Table B17: What care and services do you receive?</i>		
Administration (most packages would include this)	86%	70%
Care planning / management	73%	73%
Clinical care (such as nursing services)	31%	30%
Personal assistance (personal care, shopping etc)	78%	80%
Home maintenance (help with the house or garden)	60%	61%
Home modification (easy access taps, bath rails etc.)	27%	32%
Advice on home safety	48%	54%
Assistance with nutrition and food preparation	27%	29%
Assistance with bandages, dressings etc	19%	20%
Assistance with mobility (crutches, lifting aids etc.)	28%	31%
Assistance with leisure and recreation activities	47%	47%
Continence management	24%	32%
Therapy (speech therapy, physio, podiatry etc.)	26%	29%
Emotional support	40%	46%
On-call access	48%	60%
<i>Table B18: How many different service providers do you receive services from?</i>		
1 provider only	52%	56%
2 providers	19%	15%
3 providers	15%	9%
4 or more providers	10%	9%
Don't know / Not sure	2%	5%
Multiple response	0%	2%
Blank / No response	3%	5%
<i>Table B19: Overall, I am satisfied with the quality of care and services I receive</i>		
Strongly disagree	0%	0%
Disagree	2%	0%
Neither agree nor disagree	1%	3%
Agree	53%	44%
Strongly agree	40%	48%
Don't know	0%	1%
Not applicable to me	0%	0%
Multiple response	1%	0%
Blank / No response	4%	3%

Question / response	CDC	Comparison
<i>Table B20: I am satisfied with the way my care is planned and coordinated</i>		
Strongly disagree	0%	0%
Disagree	2%	0%
Neither agree nor disagree	1%	3%
Agree	63%	50%
Strongly agree	31%	43%
Don't know	0%	1%
Not applicable to me	0%	0%
Multiple response	1%	0%
Blank / No response	3%	3%
<i>Table B21: I would feel comfortable asking to change the type of services that I receive if I needed to, or asking for a new service</i>		
Strongly disagree	0%	0%
Disagree	2%	1%
Neither agree nor disagree	3%	3%
Agree	57%	52%
Strongly agree	33%	37%
Don't know	0%	2%
Not applicable to me	1%	1%
Multiple response	1%	1%
Blank / No response	3%	3%
<i>Table B22: I would feel comfortable asking to change one or more of the service providers that I receive services from if I needed to, or to ask for a new service provider</i>		
Strongly disagree	0%	0%
Disagree	3%	3%
Neither agree nor disagree	6%	5%
Agree	56%	48%
Strongly agree	27%	29%
Don't know	0%	5%
Not applicable to me	2%	6%
Multiple response	1%	0%
Blank / No response	5%	4%

Question / response	CDC	Comparison
<i>Table B23: I feel like I have control the care and services I receive</i>		
Strongly disagree	0%	0%
Disagree	4%	0%
Neither agree nor disagree	6%	6%
Agree	57%	56%
Strongly agree	27%	33%
Don't know	0%	2%
Not applicable to me	0%	0%
Multiple response	1%	0%
Blank / No response	5%	3%
<i>Table B24: The care and services I receive help me to do or achieve the things I want to do or achieve</i>		
Strongly disagree	0%	0%
Disagree	2%	1%
Neither agree nor disagree	5%	6%
Agree	60%	53%
Strongly agree	25%	37%
Don't know	1%	1%
Not applicable to me	2%	0%
Multiple response	1%	0%
Blank / No response	5%	3%
<i>Table B25: Being involved in consumer-directed care has helped me to do or achieve the things I want to do or achieve</i>		
Strongly disagree	0%	
Disagree	1%	
Neither agree nor disagree	9%	
Agree	60%	
Strongly agree	22%	
Don't know	0%	
Not applicable to me	3%	
Multiple response	1%	
Blank / No response	5%	

Question / response	CDC	Comparison
<i>Table B26: Compared to six months ago, how satisfied were you with your ability to achieve the things you want to achieve?</i>		
Not satisfied	2%	3%
Somewhat less satisfied	6%	8%
No different	23%	40%
Somewhat more satisfied	30%	21%
Much more satisfied	32%	23%
Don't know	1%	2%
Multiple response	1%	0%
Blank / No response	5%	2%
<i>Table B27: Compared to six months ago, how satisfied were you with the level of control that you feel you have over your care?</i>		
Not satisfied	1%	0%
Somewhat less satisfied	2%	2%
No different	19%	49%
Somewhat more satisfied	31%	25%
Much more satisfied	38%	19%
Don't know	2%	2%
Multiple response	2%	0%
Blank / No response	5%	2%
<i>Table B28: Compared to six months ago, how satisfied were you with your ability to participate in social and community activities?</i>		
Not satisfied	2%	2%
Somewhat less satisfied	6%	10%
No different	36%	45%
Somewhat more satisfied	26%	22%
Much more satisfied	23%	13%
Don't know	1%	4%
Multiple response	1%	1%
Blank / No response	6%	2%

Question / response	CDC	Comparison
<i>Table B29: Compared to six months ago, how satisfied were you with the extent which you were able to visit your family and friends?</i>		
Not satisfied	2%	4%
Somewhat less satisfied	5%	8%
No different	51%	67%
Somewhat more satisfied	25%	9%
Much more satisfied	13%	9%
Don't know	0%	2%
Multiple response	0%	0%
Blank / No response	4%	2%
<i>Table B30: Compared to six months ago, how satisfied were you with the quality of your home life and close relationships?</i>		
Not satisfied	2%	1%
Somewhat less satisfied	2%	6%
No different	45%	61%
Somewhat more satisfied	25%	16%
Much more satisfied	22%	13%
Don't know	2%	2%
Multiple response	0%	0%
Blank / No response	2%	2%
<i>Table B31: Compared to six months ago, how satisfied were you with the extent to which you can complete everyday tasks around your home?</i>		
Not satisfied	4%	5%
Somewhat less satisfied	11%	13%
No different	29%	50%
Somewhat more satisfied	27%	18%
Much more satisfied	27%	10%
Don't know	0%	1%
Multiple response	0%	0%
Blank / No response	2%	2%

Question / response	CDC	Comparison
<i>Table B32: Compared to six months ago, how satisfied were you with your general health and wellbeing?</i>		
Not satisfied	6%	6%
Somewhat less satisfied	16%	20%
No different	27%	36%
Somewhat more satisfied	29%	21%
Much more satisfied	20%	15%
Don't know	0%	1%
Multiple response	0%	0%
Blank / No response	2%	2%

<i>Table B33: Compared to six months ago, how satisfied were you with your level of independence?</i>		
Not satisfied	5%	3%
Somewhat less satisfied	12%	13%
No different	36%	55%
Somewhat more satisfied	22%	13%
Much more satisfied	21%	13%
Don't know	1%	1%
Multiple response	0%	0%
Blank / No response	3%	2%

The following items relate to aspects of a person's quality of life, and were from the ICECAP-O wellbeing measurement tool.

*Table B34: ICECAP-O wellbeing measurement tool – median scores by care level*

Care level	CDC	Comparison
CDCL/CACP	0.85	0.84
CDCH/EACH	0.70	0.63
CDCHD/EACHD	...	...
<b>Median score</b>	<b>0.77</b>	<b>0.79</b>

A score of 1 is the maximum wellbeing score, and a score of 0 the minimum  
Note that respondents who did not complete all five items have been excluded.

Table B35: Responses to ICECAP-O wellbeing measurement tool – 5 life domains

Life domain / response	CDC	Comparison
<i>Attachment</i>		
I can have all of the love and friendship that I want	48%	49%
I can have a lot of the love and friendship that I want	35%	23%
I can have a little of the love and friendship that I want	13%	18%
I cannot have any of the love and friendship that I want	1%	3%
Multiple response	0%	1%
Blank / No response	3%	6%
<i>Security</i>		
I can think about the future without any concern	19%	30%
I can think about the future with only a little concern	34%	29%
I can only think about the future with some concern	32%	20%
I can only think about the future with a lot of concern	11%	13%
Multiple response	0%	0%
Blank / No response	3%	7%
<i>Role</i>		
I am able to do all the things that make me feel valued	16%	17%
I am able to do many of the things that make me feel valued	31%	25%
I am able to do a few of the things that make me feel valued	42%	40%
I am unable to do any of the things that make me feel valued	8%	12%
Multiple response	1%	0%
Blank / No response	2%	5%
<i>Enjoyment</i>		
I can have all of the enjoyment and pleasure that I want	21%	23%
I can have a lot of the enjoyment and pleasure that I want	36%	33%
I can have a little of the enjoyment and pleasure that I want	39%	34%
I cannot have any of the enjoyment and pleasure that I want	1%	4%
Multiple response	0%	0%
Blank / No response	3%	6%
<i>Control</i>		
I am able to be completely independent	6%	9%
I am able to be independent in many things	46%	46%
I am able to be independent in a few things	31%	29%
I am unable to be at all independent	15%	10%
Multiple response	1%	1%
Blank / No response	0%	6%

### *Responses to selected survey questions, by care level*

The tables below outline the responses to selected survey questions for the CDC participant group and the packaged care comparison group, split by care level.

Note that survey responses for the CDCHD and EACHD comparison group have not been included, given there were a relatively low number of responses received to make a meaningful comparison. In addition, survey responses for people who did not indicate their care level in the surveys have been excluded.

### *Survey responses by care level*

*Table B36: Survey responses by care level*

Care level	CDC	Comparison
Low care (CDCL/CACP)	68	80
High care (CDCH/EACH)	34	29
High care (dementia) (CDCHD/EACHD)	13*	7*
Unknown	9	10
<b>Total</b>	<b>124</b>	<b>126</b>

\*note that because the number of responses received for these groups was low, responses have not been reported

Question / response	CDCL	CACP	CDCH	EACH	CDCHD	EACHD
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*Table B37: Participants by age group*

50 - 64	3%	1%	6%	0%		
65 - 74	15%	16%	27%	38%		
75 - 84	43%	37%	39%	34%		
85+	40%	46%	27%	28%		

*Table B38: Participants by special needs group*

Indigenous	0%	1%	0%	3%		
CALD	19%	14%	12%	10%		
Lives in a rural or remote area	22%	16%	12%	10%		
Veteran	12%	18%	9%	14%		
Homeless	0%	1%	0%	0%		
Financially or socially disadvantaged	62%	58%	35%	52%		
Care leaver	3%	0%	3%	0%		

*Table B39: Package history prior to CDC*

Yes	60%		45%			
No	40%		55%			

Question / response	CDCL	CACP	CDCH	EACH	CDCHD	EACHD
<i>Table B40: Why did you choose to participate in the CDC initiative</i>						
More choice of services used	29%		38%			
More choice of providers	9%		21%			
Control over planning	35%		38%			
Recommended by care provider	72%		82%			
Not satisfied with previous community care	1%		6%			

*Table B41: I felt included in the process of planning my care services*

Strongly disagree	0%	0%	0%	3%
Disagree	1%	0%	0%	0%
Neither agree nor disagree	4%	4%	0%	7%
Agree	56%	55%	53%	62%
Strongly agree	35%	39%	47%	21%
Don't know/not sure	0%	0%	0%	3%
Not applicable to me	0%	1%	0%	3%
Multiple response to single response question	0%	1%	0%	0%
Blank/no response	3%	0%	0%	0%

Question / response	CDCL	CACP	CDCH	EACH	CDCHD	EACHD
<i>Table B42: My needs and goals were taken into account in the process of planning my care and services</i>						
Strongly disagree	0%	0%	0%	0%		
Disagree	1%	0%	0%	3%		
Neither agree nor disagree	1%	1%	0%	3%		
Agree	60%	51%	47%	76%		
Strongly agree	35%	45%	53%	14%		
Don't know/not sure	0%	0%	0%	3%		
Not applicable to me	0%	1%	0%	0%		
Multiple response to single response question	0%	1%	0%	0%		
Blank/no response	1%	0%	0%	0%		

*Table B43: I was satisfied with the range of services that I could choose/I was satisfied with the range of services that were provided to me*

Strongly disagree	0%	0%	0%	0%
Disagree	3%	3%	9%	0%
Neither agree nor disagree	4%	0%	3%	7%
Agree	69%	51%	50%	76%
Strongly agree	22%	44%	35%	17%
Don't know/not sure	0%	0%	3%	0%
Not applicable to me	0%	0%	0%	0%
Multiple response to single response question	0%	1%	0%	0%
Blank/no response	1%	1%	0%	0%

Question / response	CDCL	CACP	CDCH	EACH	CDCHD	EACHD
<i>Table B44: I received the services I wanted to receive</i>						
Strongly disagree	0%	1%	0%	0%		
Disagree	3%	1%	3%	3%		
Neither agree nor disagree	9%	4%	0%	7%		
Agree	59%	51%	53%	72%		
Strongly agree	26%	41%	41%	17%		
Don't know/not sure	0%	0%	0%	0%		
Not applicable to me	0%	0%	0%	0%		
Multiple response to single response question	0%	1%	0%	0%		
Blank/no response	3%	0%	3%	0%		

*Table B45: Overall, I felt confident in making decisions about my care package and providers*

Strongly disagree	0%	0%
Disagree	4%	0%
Neither agree nor disagree	4%	0%
Agree	63%	47%
Strongly agree	25%	47%
Don't know/not sure	0%	0%
Not applicable to me	0%	0%
Multiple response to single response question	0%	0%
Blank/no response	3%	6%

Question / response	CDCL	CACP	CDCH	EACH	CDCHD	EACHD
<i>Table B46: Overall, I am satisfied with the quality of care and services I receive</i>						
Strongly disagree	0%	0%	0%	0%		
Disagree	1%	0%	3%	0%		
Neither agree nor disagree	0%	1%	0%	7%		
Agree	60%	44%	47%	55%		
Strongly agree	35%	51%	44%	34%		
Don't know/not sure	0%	0%	0%	0%		
Not applicable to me	0%	0%	0%	0%		
Multiple response to single response question	0%	0%	0%	0%		
Blank/no response	3%	4%	6%	3%		

*Table B47: I feel like I have control the care and services I receive*

Strongly disagree	0%	0%	0%	0%
Disagree	4%	0%	3%	0%
Neither agree nor disagree	7%	4%	3%	10%
Agree	65%	55%	50%	69%
Strongly agree	18%	36%	44%	17%
Don't know/not sure	0%	1%	0%	0%
Not applicable to me	0%	0%	0%	0%
Multiple response to single response question	0%	0%	0%	0%
Blank/no response	6%	4%	0%	3%

Question / response	CDCL	CACP	CDCH	EACH	CDCHD	EACHD
<i>Table B48: The care and services I receive help me to do or achieve the things I want to do or achieve</i>						
Strongly disagree	0%	0%	0%	0%		
Disagree	3%	1%	0%	0%		
Neither agree nor disagree	3%	4%	0%	10%		
Agree	68%	49%	65%	76%		
Strongly agree	18%	43%	32%	10%		
Don't know/not sure	1%	0%	0%	0%		
Not applicable to me	1%	0%	3%	0%		
Multiple response to single response question	0%	0%	0%	0%		
Blank/no response	6%	4%	0%	3%		

*Table B49: Being involved in consumer-directed care has helped me to do or achieve the things I want to do or achieve*

Strongly disagree	0%	0%
Disagree	1%	0%
Neither agree nor disagree	12%	0%
Agree	65%	62%
Strongly agree	13%	32%
Don't know/not sure	0%	0%
Not applicable to me	3%	6%
Multiple response to single response question	0%	0%
Blank/no response	6%	0%

Question / response	CDCL	CACP	CDCH	EACH	CDCHD	EACHD
<i>Table B50: Compared to six months ago, how satisfied are you with your ability to achieve the things you want to achieve?</i>						
Not satisfied	3%	3%	3%	3%		
Somewhat less satisfied	4%	6%	9%	10%		
No different	28%	39%	21%	45%		
Somewhat more satisfied	31%	23%	24%	24%		
Much more satisfied	28%	26%	38%	14%		
Don't know	0%	1%	0%	3%		
Multiple response to single response question	0%	0%	3%	0%		
Blank / No response	6%	3%	3%	0%		

*Table B51: Compared to six months ago, how satisfied are you with the level of control that you feel you have over your care?*

Not satisfied	1%	0%	0%	0%
Somewhat less satisfied	4%	1%	0%	7%
No different	22%	44%	15%	62%
Somewhat more satisfied	29%	29%	35%	24%
Much more satisfied	35%	23%	41%	3%
Don't know	1%	1%	3%	3%
Multiple response to single response question	0%	0%	3%	0%
Blank / No response	6%	3%	3%	0%

Question / response	CDCL	CACP	CDCH	EACH	CDCHD	EACHD
<i>Table B52: Compared to six months ago, how satisfied are you with your ability to participate in social and community activities?</i>						
Not satisfied	3%	1%	3%	3%		
Somewhat less satisfied	3%	10%	6%	17%		
No different	40%	41%	32%	55%		
Somewhat more satisfied	31%	26%	26%	14%		
Much more satisfied	18%	16%	24%	3%		
Don't know	1%	1%	0%	3%		
Multiple response to single response question	0%	1%	0%	0%		
Blank / No response	4%	3%	9%	3%		
Total						

*Table B53: Compared to six months ago, how satisfied are you with the extent which you are able to visit your family and friends?*

Not satisfied	3%	1%	3%	10%
Somewhat less satisfied	3%	9%	9%	7%
No different	56%	68%	29%	69%
Somewhat more satisfied	26%	8%	35%	7%
Much more satisfied	7%	11%	21%	3%
Don't know	0%	1%	0%	0%
Multiple response to single response question	4%	3%	3%	3%
Blank / No response	0%	0%	0%	0%

Question / response	CDCL	CACP	CDCH	EACH	CDCHD	EACHD
<i>Table B54: Compared to six months ago, how satisfied are you with the quality of your home life and close relationships?</i>						
Not satisfied	3%	0%	0%	3%		
Somewhat less satisfied	1%	5%	3%	7%		
No different	46%	59%	50%	69%		
Somewhat more satisfied	25%	18%	18%	14%		
Much more satisfied	19%	16%	29%	7%		
Don't know	3%	0%	0%	0%		
Multiple response to single response question	0%	0%	0%	0%		
Blank / No response	3%	3%	0%	0%		

*Table B55: Compared to six months ago, how satisfied are you with the extent to which you can complete everyday tasks around your home?*

Not satisfied	4%	3%	3%	14%
Somewhat less satisfied	9%	13%	12%	10%
No different	25%	50%	35%	48%
Somewhat more satisfied	32%	20%	21%	21%
Much more satisfied	26%	13%	29%	3%
Don't know	0%	0%	0%	0%
Multiple response to single response question	0%	0%	0%	0%
Blank / No response	3%	3%	0%	3%

Question / response	CDCL	CACP	CDCH	EACH	CDCHD	EACHD
<i>Table B56: Compared to six months ago, how satisfied are you with your general health and wellbeing?</i>						
Not satisfied	7%	4%	3%	14%		
Somewhat less satisfied	15%	23%	15%	14%		
No different	26%	30%	35%	52%		
Somewhat more satisfied	35%	25%	21%	14%		
Much more satisfied	15%	16%	26%	7%		
Don't know	0%	0%	0%	0%		
Multiple response to single response question	0%	0%	0%	0%		
Blank / No response	1%	3%	0%	0%		

*Table B57: Compared to six months ago, how satisfied are you with your level of independence?*

Not satisfied	6%	3%	3%	7%
Somewhat less satisfied	10%	11%	15%	21%
No different	41%	55%	29%	62%
Somewhat more satisfied	19%	16%	32%	3%
Much more satisfied	19%	13%	18%	7%
Don't know	0%	0%	3%	0%
Multiple response to single response question	0%	0%	0%	0%
Blank / No response	4%	3%	0%	0%

### Responses to selected survey questions, by packaged care history

The tables below outline the responses to *selected* survey questions for the CDC participant group, split by package care history – that is, responses for participants who received a standard packaged care package (CACP, EACH, or EACHD) prior to commencing on a CDC package, and responses for participants who did not received a standard packaged care package prior to commencing on a CDC package.

Survey responses for participants who did not indicate their packaged care history in the surveys have been excluded.

Question / response	Received packaged care	Had not received packaged care
<i>Table B58: Why did you choose to participate in the CDC initiative</i>		
More choice of services used	41%	30%
More choice of providers	16%	18%
Control over planning	46%	34%
Recommended by care provider	70%	75%
Not satisfied with previous community care	11%	2%

<i>Table B59: I felt included in the process of planning my care services</i>		
Strongly disagree	0%	0%
Disagree	2%	0%
Neither agree nor disagree	8%	0%
Agree	51%	58%
Strongly agree	36%	42%
Don't know/not sure	0%	0%
Not applicable to me	0%	0%
Multiple response to single response question	2%	0%
Blank/no response	2%	0%

Question / response	Received packaged care	Had not received packaged care
<i>Table B60: My needs and goals were taken into account in the process of planning my care and services</i>		
Strongly disagree	0%	0%
Disagree	0%	2%
Neither agree nor disagree	3%	0%
Agree	56%	53%
Strongly agree	37%	44%
Don't know/not sure	0%	0%
Not applicable to me	0%	0%
Multiple response to single response question	2%	0%
Blank/no response	2%	0%

*Table B61: I was satisfied with the range of services that I could choose/I am satisfied with the range of services that were provided to me*

Strongly disagree	0%	0%
Disagree	7%	4%
Neither agree nor disagree	8%	0%
Agree	54%	71%
Strongly agree	27%	22%
Don't know/not sure	0%	2%
Not applicable to me	0%	0%
Multiple response to single response question	2%	0%
Blank/no response	2%	0%

Question / response	Received packaged care	Had not received packaged care
<i>Table B62: I received the services I wanted to receive</i>		
Strongly disagree	0%	0%
Disagree	7%	2%
Neither agree nor disagree	7%	4%
Agree	54%	58%
Strongly agree	29%	33%
Don't know/not sure	0%	0%
Not applicable to me	0%	0%
Multiple response to single response question	0%	0%
Blank/no response	3%	2%

<i>Table B63: Overall, I felt confident in making decisions about my care package and providers</i>		
Strongly disagree	0%	0%
Disagree	3%	2%
Neither agree nor disagree	5%	4%
Agree	54%	58%
Strongly agree	32%	33%
Don't know/not sure	0%	0%
Not applicable to me	0%	0%
Multiple response to single response question	0%	0%
Blank/no response	5%	2%

Question / response	Received packaged care	Had not received packaged care
<i>Table B64: Overall, I am satisfied with the quality of care and services I receive</i>		
Strongly disagree	0%	0%
Disagree	3%	0%
Neither agree nor disagree	2%	0%
Agree	59%	49%
Strongly agree	31%	47%
Don't know/not sure	0%	0%
Not applicable to me	0%	0%
Multiple response to single response question	2%	0%
Blank/no response	3%	4%

*Table B65: I feel like I have control the care and services I receive*

Strongly disagree	0%	0%
Disagree	5%	4%
Neither agree nor disagree	3%	0%
Agree	66%	60%
Strongly agree	19%	33%
Don't know/not sure	0%	0%
Not applicable to me	0%	0%
Multiple response to single response question	2%	0%
Blank/no response	5%	2%

Question / response	Received packaged care	Had not received packaged care
<i>Table B66: The care and services I receive help me to do or achieve the things I want to do or achieve</i>		
Strongly disagree	0%	0%
Disagree	3%	0%
Neither agree nor disagree	3%	2%
Agree	63%	67%
Strongly agree	22%	24%
Don't know/not sure	0%	2%
Not applicable to me	0%	4%
Multiple response to single response question	2%	0%
Blank/no response	7%	0%

<i>Table B67: Being involved in consumer-directed care has helped me to do or achieve the things I want to do or achieve</i>		
Strongly disagree	0%	0%
Disagree	2%	0%
Neither agree nor disagree	8%	9%
Agree	63%	60%
Strongly agree	19%	22%
Don't know/not sure	0%	9%
Not applicable to me	0%	0%
Multiple response to single response question	2%	0%
Blank/no response	7%	0%

Question / response	Received packaged care	Had not received packaged care
<i>Table B68: Compared to six months ago, how satisfied are you with your ability to achieve the things you want to achieve?</i>		
Not satisfied	0%	7%
Somewhat less satisfied	3%	7%
No different	22%	27%
Somewhat more satisfied	32%	27%
Much more satisfied	36%	27%
Don't know	0%	2%
Multiple response to single response question	2%	0%
Blank / No response	5%	4%

*Table B69: Compared to six months ago, how satisfied are you with the level of control that you feel you have over your care?*

Not satisfied	0%	2%
Somewhat less satisfied	2%	2%
No different	17%	20%
Somewhat more satisfied	36%	31%
Much more satisfied	37%	36%
Don't know	0%	4%
Multiple response to single response question	3%	0%
Blank / No response	5%	4%

Question / response	Received packaged care	Had not received packaged care
<i>Table B70: Compared to six months ago, how satisfied are you with your ability to participate in social and community activities?</i>		
Not satisfied	0%	7%
Somewhat less satisfied	3%	7%
No different	39%	38%
Somewhat more satisfied	34%	18%
Much more satisfied	19%	24%
Don't know	0%	0%
Multiple response to single response question	0%	0%
Blank / No response	5%	7%

<i>Table B71: Compared to six months ago, how satisfied are you with the extent which you are able to visit your family and friends?</i>		
Not satisfied	0%	7%
Somewhat less satisfied	3%	7%
No different	47%	56%
Somewhat more satisfied	32%	16%
Much more satisfied	12%	13%
Don't know	0%	0%
Multiple response to single response question	0%	0%
Blank / No response	5%	2%

Question / response	Received packaged care	Had not received packaged care
<i>Table B72: Compared to six months ago, how satisfied are you with the quality of your home life and close relationships?</i>		
Not satisfied	0%	4%
Somewhat less satisfied	2%	2%
No different	41%	53%
Somewhat more satisfied	29%	20%
Much more satisfied	22%	20%
Don't know	3%	0%
Multiple response to single response question	0%	0%
Blank / No response	3%	0%

*Table B73: Compared to six months ago, how satisfied are you with the extent to which you can complete everyday tasks around your home?*

Not satisfied	2%	9%
Somewhat less satisfied	7%	9%
No different	29%	33%
Somewhat more satisfied	31%	24%
Much more satisfied	31%	22%
Don't know	0%	0%
Multiple response to single response question	0%	0%
Blank / No response	2%	2%

Question / response	Received packaged care	Had not received packaged care
<i>Table B74: Compared to six months ago, how satisfied are you with your general health and wellbeing?</i>		
Not satisfied	2%	11%
Somewhat less satisfied	14%	18%
No different	27%	33%
Somewhat more satisfied	39%	18%
Much more satisfied	17%	20%
Don't know	0%	0%
Multiple response to single response question	0%	0%
Blank / No response	2%	0%

<i>Table B75: Compared to six months ago, how satisfied are you with your level of independence?</i>		
Not satisfied	2%	11%
Somewhat less satisfied	10%	11%
No different	39%	38%
Somewhat more satisfied	20%	24%
Much more satisfied	24%	13%
Don't know	2%	0%
Multiple response to single response question	0%	0%
Blank / No response	3%	2%

## B.3 Consumer-directed respite care and comparison group survey responses

### *Respondent characteristics*

The tables below outline the characteristics of respondents to the CDRC participant survey and the NRCP comparison group survey.

*Table B76: Respondent characteristics – CDRC*

Characteristic	CDRC	Comparison
<i>Age</i>		
under 50	12%	5%
50-64	43%	47%
65-74	23%	24%
75-84	18%	18%
85+	2%	2%
Blank / No response	1%	4%
<i>Gender</i>		
Male	26%	31%
Female	74%	64%
Multiple response	0%	0%
Blank / No response	0%	5%
<i>Pension status</i>		
I receive a full Centrelink pension	37%	40%
I received a part Centrelink pension	22%	24%
I receive another type of pension	5%	9%
I do not receive a pension	24%	18%
Multiple response	7%	2%
Blank / No response	5%	7%
<i>Special needs group status</i>		
I am of Aboriginal and / or Torres Strait Islander origin	5%	2%
I was born in a non-English speaking country	7%	22%
I live in a rural or remote area	25%	25%
I am a Veteran, a spouse / partner of a Veteran or a widow / widower of a Veteran	5%	2%
I have no permanent accommodation, and live in temporary accommodation	0%	0%
I have no permanent or conventional accommodation	0%	0%
I was raised in an orphanage, out-of-home care or foster care	0%	0%

Characteristic	CDRC	Comparison
<i>Do you have someone who does not live with you whom you can call on for assistance during a crisis?</i>		
Yes	71%	85%
No	29%	11%
Multiple response	0%	0%
Blank / No response	0%	4%
<i>Age of the person cared for</i>		
under 50	1%	7%
50-64	9%	7%
65-74	24%	24%
75-84	33%	29%
85+	26%	20%
Multiple / blank	8%	13%
<i>Gender of the person cared for</i>		
Male	49%	47%
Female	45%	40%
Multiple response	5%	9%
Blank / No response	1%	4%
<i>Living arrangements</i>		
Lives with the person cared for	83%	84%
Does not live with the person cared for	16%	15%
Multiple response	1%	0%
Blank / No response	0%	2%
<i>Relationship with the person care for</i>		
Spouse / partner	58%	65%
Parent	30%	25%
Grandparent	0%	0%
Sibling	1%	4%
Extended family member	0%	2%
Friend	0%	0%
Multiple response	1%	2%
Blank / No response	10%	2%
<i>Dementia status – person cared for</i>		
Has dementia	54%	51%
Does not have dementia	45%	45%
Multiple response	0%	2%
Blank / No response	1%	2%

Characteristic	CDRC	Comparison
<i>Disability status – person cared for</i>		
Has a disability	68%	76%
Does not have a disability	25%	22%
Multiple response	0%	0%
Blank / No response	7%	2%
<i>Pension status - person cared for</i>		
Full Centrelink pension	46%	53%
Part Centrelink pension	24%	24%
Another type of pension	14%	5%
Does not receive a pension	10%	7%
Multiple response	3%	5%
Blank / No response	3%	5%
<i>Pension type – person cared for</i>		
Age pension	64%	55%
Disability support pension	5%	16%
Widow pension	1%	2%
Carer Payment / Allowance	1%	4%
Private pension / superannuation	5%	4%
Multiple response	7%	11%
Blank / No response	16%	9%
<i>Special needs group status - person cared for</i>		
Aboriginal and / or Torres Strait Islander origin	3%	2%
Born in a non-English speaking country	11%	18%
Live in a rural or remote area	23%	29%
Veteran, a spouse / partner of a Veteran or a widow / widower of a Veteran	12%	4%
No permanent accommodation, and live in temporary accommodation	0%	2%
No permanent or conventional accommodation	0%	0%
Raised in an orphanage, out-of-home care or foster care (care-leaver)	0%	0%

*Table B77: Did you use any respite services before you started using Consumer Directed Respite Care?*

Response	CDRC	Comparison
Yes - In home respite	76%	
Yes - Out of home respite	26%	
Yes - Holiday respite	18%	
Yes - Residential aged care respite	18%	

*Table B78: Length of time receiving current respite package / respite services*

Response	CDRC	Comparison
Less than 1 month	0%	5%
1 to 3 months	17%	13%
3 to 6 months	36%	13%
More than 6 months	45%	65%
Multiple response	2%	0%
Blank / No response	0%	4%

### **Responses to survey questions**

The tables below outline the responses to each survey question for the CDRC participant group and the NRCPC comparison group.

In most cases, the same question was asked in each survey, though there were some additional questions included in the CDRC participant survey only.

Question / response	CDRC	Comparison
<i>Table B79: Why did you decide to participate in Consumer Directed Respite Care?</i>		
I wanted more choice of which respite service I used	35%	
I wanted to have more choice of providers	15%	
I wanted more control over my respite planning	34%	
It was recommended to me by the Carelink Centre	52%	
I was not satisfied with my previous respite care	7%	

*Table B80: I felt included in the process of planning my respite services*

Strongly disagree	1%	4%
Disagree	2%	2%
Neither agree nor disagree	2%	4%
Agree	27%	62%
Strongly agree	66%	22%
Don't know	0%	0%
Not applicable to me	0%	4%
Multiple response	0%	2%
Blank / No response	1%	2%

Question / response	CDRC	Comparison
<i>Table B81: My needs and goals were taken into account in the process of planning my respite services</i>		
Strongly disagree	2%	4%
Disagree	2%	5%
Neither agree nor disagree	2%	5%
Agree	26%	62%
Strongly agree	67%	20%
Don't know	0%	0%
Not applicable to me	0%	2%
Multiple response	0%	0%
Blank / No response	0%	2%

*Table B82: I had enough information about the types of services that I could choose*

Strongly disagree	2%
Disagree	2%
Neither agree nor disagree	3%
Agree	33%
Strongly agree	58%
Don't know	1%
Not applicable to me	0%
Multiple response	1%
Blank / No response	0%

*Table B83: I had enough information about the respite service providers that I could choose to receive services from*

Strongly disagree	2%
Disagree	7%
Neither agree nor disagree	11%
Agree	41%
Strongly agree	34%
Don't know	2%
Not applicable to me	2%
Multiple response	0%
Blank / No response	1%

Question / response	CDRC	Comparison
<i>Table B84: I had enough information about the costs involved</i>		
Strongly disagree	1%	
Disagree	3%	
Neither agree nor disagree	7%	
Agree	39%	
Strongly agree	41%	
Don't know	2%	
Not applicable to me	5%	
Multiple response	0%	
Blank / No response	1%	
<i>Table B85: I had enough information about how frequently I could access respite</i>		
Strongly disagree	1%	
Disagree	4%	
Neither agree nor disagree	4%	
Agree	46%	
Strongly agree	41%	
Don't know	1%	
Not applicable to me	1%	
Multiple response	0%	
Blank / No response	1%	
<i>Table B86: The Commonwealth Respite and Carelink Centre helped me to plan and make decisions regarding the types of respite services I could choose</i>		
Strongly disagree	2%	
Disagree	2%	
Neither agree nor disagree	3%	
Agree	33%	
Strongly agree	55%	
Don't know	1%	
Not applicable to me	2%	
Multiple response	0%	
Blank / No response	1%	

Question / response	CDRC	Comparison
<i>Table B87: I was satisfied with the amount of help I received from the Commonwealth Respite and Carelink Centre</i>		
Strongly disagree	1%	
Disagree	0%	
Neither agree nor disagree	4%	
Agree	29%	
Strongly agree	62%	
Don't know	0%	
Not applicable to me	2%	
Multiple response	0%	
Blank / No response	1%	
<i>Table B88: I was satisfied with the range of respite services that I could choose</i>		
Strongly disagree	2%	5%
Disagree	8%	9%
Neither agree nor disagree	7%	2%
Agree	33%	62%
Strongly agree	46%	16%
Don't know	2%	2%
Not applicable to me	2%	2%
Multiple response	0%	0%
Blank / No response	1%	2%
<i>Table B89: I am satisfied with the service providers that deliver respite services</i>		
Strongly disagree	1%	2%
Disagree	7%	4%
Neither agree nor disagree	4%	7%
Agree	35%	49%
Strongly agree	51%	29%
Don't know	0%	2%
Not applicable to me	1%	2%
Multiple response	0%	4%
Blank / No response	1%	2%

Question / response	CDRC	Comparison
<i>Table B90: I receive the respite services that I wanted to receive</i>		
Strongly disagree	2%	5%
Disagree	4%	13%
Neither agree nor disagree	5%	4%
Agree	39%	45%
Strongly agree	47%	25%
Don't know	0%	2%
Not applicable to me	0%	2%
Multiple response	0%	2%
Blank / No response	2%	2%
<i>Table B91: Overall, I felt confident making decisions about my respite services</i>		
Strongly disagree	1%	
Disagree	2%	
Neither agree nor disagree	5%	
Agree	43%	
Strongly agree	47%	
Don't know	0%	
Not applicable to me	0%	
Multiple response	0%	
Blank / No response	1%	
<i>Table B92: Overall, I am satisfied with the quality of respite services I receive</i>		
Strongly disagree	1%	4%
Disagree	2%	4%
Neither agree nor disagree	2%	9%
Agree	37%	45%
Strongly agree	55%	31%
Don't know	1%	0%
Not applicable to me	0%	2%
Multiple response	0%	4%
Blank / No response	1%	2%

Question / response	CDRC	Comparison
<i>Table B93: I am satisfied with the way my respite care is planned and coordinated</i>		
Strongly disagree	2%	4%
Disagree	3%	7%
Neither agree nor disagree	1%	5%
Agree	40%	53%
Strongly agree	51%	27%
Don't know	1%	0%
Not applicable to me	0%	2%
Multiple response	0%	0%
Blank / No response	1%	2%
<i>Table B94: I would feel comfortable asking to change the type of services that I receive if I needed to, or asking for a new type of service</i>		
Strongly disagree	1%	4%
Disagree	2%	5%
Neither agree nor disagree	0%	5%
Agree	41%	56%
Strongly agree	51%	24%
Don't know	0%	2%
Not applicable to me	1%	2%
Multiple response	1%	0%
Blank / No response	2%	2%
<i>Table B95: I would feel comfortable asking to change the frequency of services that I receive if I needed to</i>		
Strongly disagree	1%	4%
Disagree	3%	9%
Neither agree nor disagree	1%	5%
Agree	37%	58%
Strongly agree	53%	9%
Don't know	1%	9%
Not applicable to me	1%	4%
Multiple response	0%	0%
Blank / No response	2%	2%

Question / response	CDRC	Comparison
<i>Table B96: I feel like I have control over my respite plan, and the respite services I receive</i>		
Strongly disagree	1%	5%
Disagree	3%	15%
Neither agree nor disagree	8%	7%
Agree	37%	55%
Strongly agree	48%	13%
Don't know	0%	0%
Not applicable to me	1%	2%
Multiple response	0%	0%
Blank / No response	2%	4%

*Table B97: The respite services I receive help me to do or achieve the things I want to do or achieve*

Strongly disagree	1%	4%
Disagree	1%	7%
Neither agree nor disagree	4%	4%
Agree	43%	58%
Strongly agree	48%	20%
Don't know	0%	4%
Not applicable to me	0%	2%
Multiple response	0%	0%
Blank / No response	2%	2%

*Table B98: Being involved in Consumer Directed Respite Care has helped me to do or achieve the things I want to do or achieve*

Strongly disagree	1%
Disagree	3%
Neither agree nor disagree	4%
Agree	36%
Strongly agree	54%
Don't know	0%
Not applicable to me	0%
Multiple response	0%
Blank / No response	1%

Question / response	CDRC	Comparison
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*Table B99: Compared to six months ago, how satisfied were you with your ability to achieve the things you want to achieve?*

Not satisfied	3%	13%
Somewhat less satisfied	3%	15%
No different	14%	35%
Somewhat more satisfied	23%	20%
Much more satisfied	53%	13%
Don't know	2%	4%
Multiple response	0%	0%
Blank / No response	1%	2%

*Table B100: Compared to six months ago, how satisfied were you with the level of control that you feel you have over your use of respite?*

Not satisfied	3%	7%
Somewhat less satisfied	0%	7%
No different	15%	40%
Somewhat more satisfied	23%	24%
Much more satisfied	54%	18%
Don't know	1%	2%
Multiple response	0%	0%
Blank / No response	3%	2%

*Table B101: Compared to six months ago, how satisfied were you with your ability to participate in social and community activities?*

Not satisfied	3%	16%
Somewhat less satisfied	8%	15%
No different	20%	36%
Somewhat more satisfied	28%	25%
Much more satisfied	35%	5%
Don't know	4%	2%
Multiple response	0%	0%
Blank / No response	2%	0%

*Table B102: Compared to six months ago, how satisfied were you with the extent to which you were able to visit your family and friends?*

Not satisfied	3%	3%
Somewhat less satisfied	2%	2%
No different	33%	33%
Somewhat more satisfied	28%	28%
Much more satisfied	27%	27%
Don't know	2%	2%
Multiple response	0%	0%
Blank / No response	4%	4%

Question / response	CDRC	Comparison
<i>Table B103: Compared to six months ago, how satisfied were you with the quality of your home life and close relationships?</i>		
Not satisfied	5%	11%
Somewhat less satisfied	5%	16%
No different	27%	42%
Somewhat more satisfied	32%	20%
Much more satisfied	26%	9%
Don't know	0%	2%
Multiple response	0%	0%
Blank / No response	4%	0%
<i>Table B104: Compared to six months ago, how satisfied were you with the extent to which you can complete everyday tasks around your home?</i>		
Not satisfied	1%	7%
Somewhat less satisfied	5%	16%
No different	37%	45%
Somewhat more satisfied	29%	24%
Much more satisfied	24%	7%
Don't know	0%	0%
Multiple response	0%	0%
Blank / No response	3%	0%
<i>Table B105: Compared to six months ago, how satisfied were you with your general health and wellbeing?</i>		
Not satisfied	3%	11%
Somewhat less satisfied	8%	36%
No different	36%	36%
Somewhat more satisfied	30%	11%
Much more satisfied	20%	5%
Don't know	0%	0%
Multiple response	0%	0%
Blank / No response	3%	0%
<i>Table B106: Compared to six months ago, how satisfied were you with your level of independence?</i>		
Not satisfied	3%	13%
Somewhat less satisfied	5%	18%
No different	29%	45%
Somewhat more satisfied	36%	15%
Much more satisfied	22%	9%
Don't know	0%	0%
Multiple response	0%	0%
Blank / No response	4%	0%

Question / response	CDRC	Comparison
<i>Table B107: Have you, or the person you care for, experienced a major change in your life circumstances in the last six months?</i>		
Yes	45%	49%
No	52%	49%
Multiple response	0%	0%
Blank / No response	3%	2%

The following items relate to aspects of a person's quality of life, and were from the ICECAP-O wellbeing measurement tool.

*Table B108: ICECAP-O wellbeing measurement tool – median scores*

	CDRC	Comparison
Median score	0.76	0.71

A score of 1 is the maximum wellbeing score, and a score of 0 the minimum

Note that respondents who did not complete all five items have been excluded.

*Table B109: ICECAP-O wellbeing measurement tool – responses to 5 life domains*

Life domain	CDRC	Comparison
<i>Attachment</i>		
I can have all of the love and friendship that I want	28%	31%
I can have a lot of the love and friendship that I want	32%	29%
I can have a little of the love and friendship that I want	29%	29%
I cannot have any of the love and friendship that I want	3%	5%
Multiple response	1%	0%
Blank / No response		
<i>Security</i>		
I can think about the future without any concern	10%	11%
I can think about the future with only a little concern	23%	16%
I can only think about the future with some concern	42%	44%
I can only think about the future with a lot of concern	21%	24%
Multiple response	1%	0%
Blank / No response	3%	5%
<i>Role</i>		
I am able to do all the things that make me feel valued	15%	11%
I am able to do many of the things that make me feel valued	50%	47%
I am able to do a few of the things that make me feel valued	29%	29%
I am unable to do any of the things that make me feel valued	2%	7%
Multiple response	0%	0%
Blank / No response	3%	5%

Life domain	CDRC	Comparison
<i>Enjoyment</i>		
I can have all of the enjoyment and pleasure that I want	9%	2%
I can have a lot of the enjoyment and pleasure that I want	30%	33%
I can have a little of the enjoyment and pleasure that I want	57%	49%
I cannot have any of the enjoyment and pleasure that I want	3%	11%
Multiple response	1%	0%
Blank / No response	0%	5%
<i>Control</i>		
I am able to be completely independent	18%	18%
I am able to be independent in many things	38%	40%
I am able to be independent in a few things	37%	24%
I am unable to be at all independent	4%	11%
Multiple response	0%	0%
Blank / No response	2%	7%

## C. CDC and CDRC provider data collection

This section provides some preliminary data relating to the CDC and CDRC packages that had been allocated to consumers and carers during the periods 1 April to 30 June 2011 and 1 July to 30 September 2011, sourced from the first and second service provider data collections conducted as part of the Evaluation.

### C.1 Responses received

All CDC and CDRC providers were required to complete a data collection template for each of the two quarters. The table below outlines the number of organisations returning a template, and the number of packages that were allocated to participants at the end of each data collection period. The table shows that:

- 35 CDC organisations submitted data as part of the first CDC data collection, accounting for 350 packages or 70 per cent of total packages allocated to providers
- 37 CDC organisations submitted data as part of the second CDC data collection, accounting for 441 packages, or 88 per cent of total packages allocated to providers
- 13 CDRC organisations submitted data as part of the first CDRC data collection, accounting for 170 packages, or 85 per cent of total packages allocated to providers
- 15 organisations submitted data as part of the second CDRC data collection, accounting for 188 packages, or 90 per cent of total packages allocated to providers.

*Table C1: Responses submitted for CDC/CDRC provider data collections*

	Apr-June	July-Sept	No of providers/ packages funded
CDC providers submitting data	35	37	43
<i>CDC packages allocated to providers*</i>	<i>350 (70%)</i>	<i>441 (88%)</i>	<i>500</i>
CDRC providers submitting data	13	15	16
<i>CDRC packages allocated to providers*</i>	<i>170 (85%)</i>	<i>188 (90%)</i>	<i>200</i>

\*Note that not all of these packages had been allocated to participants

## C.2 Consumer-directed care – participants, services and expenditure

The following tables relate to the characteristics of CDRC participants and the services they use, as reported by CDRC providers as part of the April-June and July-September provider data collections undertaken as part of this evaluation.

*Table C2: Participants by care level*

	April-June		July-Sept		Allocated		Packaged Care (2010-11)
CDCL	186	56%	186	51%	300	60%	81%
CDCH	101	30%	126	34%	128	26%	14%
CDCHD	48	14%	54	15%	72	14%	6%
<b>Total</b>	<b>335</b>	<b>100%</b>	<b>366</b>	<b>100%</b>	<b>500</b>	<b>100%</b>	<b>100%</b>

Table C3: CDC participants by age group, by care level

	April-June				July-September			
	CDCL	CDCH	CDCHD	Total	CDCL	CDCH	CDCHD	Total
Under 50	0	1	0	1	2	2	0	4
50 - 54	0	0	0	0	0	0	0	0
55 - 59	0	2	1	3	0	4	1	5
60 - 64	2	1	4	7	0	5	3	8
65 - 69	13	7	0	20	12	9	0	21
70 - 74	13	10	4	27	12	16	3	31
75 - 79	38	19	12	69	39	25	11	75
80 - 84	54	23	11	88	56	28	11	95
85 - 89	41	14	11	66	42	18	14	74
90+	16	14	4	34	22	18	11	51
Unknown	9	10	1	20	1	1	0	2
<b>Total</b>	<b>186</b>	<b>101</b>	<b>48</b>	<b>335</b>	<b>186</b>	<b>126</b>	<b>54</b>	<b>366</b>

Table C4: CDC participants by age group, by care level – percentages

	CDCL		CACP	CDCH		EACH	CDCHD		EACHD	CDC Total		Packaged care
	Apr-June	Jul-Sept	(2010-11)	Apr-June	Jul-Sept	(2010-11)	Apr-June	Jul-Sept	(2010-11)	Apr-June	Jul-Sept	(2010-11)
Under 50	0%	1%	1%	1%	2%	0%	0%	0%	0%	0%	1%	1%
50 - 54	0%	0%	1%	0%	0%	1%	0%	0%	0%	0%	0%	1%
55 - 59	0%	0%	1%	2%	3%	1%	2%	2%	1%	1%	1%	1%
60 - 64	1%	0%	2%	1%	4%	4%	8%	6%	3%	2%	2%	2%
65 - 69	7%	6%	5%	7%	7%	8%	0%	0%	5%	6%	6%	6%
70 - 74	7%	6%	9%	10%	13%	12%	8%	6%	11%	8%	8%	10%
75 - 79	20%	21%	15%	19%	20%	16%	25%	20%	16%	21%	20%	15%
80 - 84	29%	30%	24%	23%	22%	21%	23%	20%	26%	26%	26%	24%
85 - 89	22%	23%	26%	14%	14%	20%	23%	26%	24%	20%	20%	25%
90+	9%	12%	17%	14%	14%	17%	8%	20%	13%	10%	14%	17%
Unknown	5%	1%	...	10%	1%	...	2%	0%	...	6%	1%	...
<b>Total</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>

Table C5: CDC participants by special needs group status, by care level

	April-June				July-September			
	CDCL	CDCH	CDCHD	Total	CDCL	CDCH	CDCHD	Total
ATSI	5	2	0	7	3	2	0	5
Financially/socially disadvantaged	40	20	8	68	37	23	9	69
Homeless (or at risk of homelessness)	9	2	0	11	9	1	0	10
Live in a rural/remote area	33	15	7	55	35	15	4	54
NESB	34	20	13	67	28	23	13	64
Veteran	2	3	0	5	4	4	1	9
Careleaver	0	0	0	0	0	0	0	0

Table C6: CDC participants by special needs group status, by care level - percentages

	April-June				July-Sept				Packaged care (2010-11)
	CDCL	CDCH	CDCHD	Total	CDCL	CDCH	CDCHD	Total	
ATSI	3%	2%	0%	2%	2%	2%	0%	1%	3%
Financially/socially disadvantaged	22%	20%	17%	20%	20%	18%	17%	19%	...
Homeless (or at risk of homelessness)	5%	2%	0%	3%	5%	1%	0%	3%	...
Live in a rural/remote area	18%	15%	15%	16%	19%	12%	7%	15%	...
NESB	18%	20%	27%	20%	15%	18%	24%	17%	23%
Veteran	1%	3%	0%	1%	2%	3%	2%	2%	...
Careleaver	0%	0%	0%	0%	0%	0%	0%	0%	...

Table C7: CDC participants by prior service status

	April-June				July-September			
	CDCL	CDCH	CDCHD	Total	CDCL	CDCH	CDCHD	Total
Did not receive services	56	18	8	82	45	34	8	87
Received CACP	68	24	6	98	62	28	11	101
Received EACH	1	13	5	19	2	21	1	24
Received EACHD		1	12	13		1	12	13
Received HACC or other community care	44	30	10	84	62	32	16	110
Other	5	6	3	14	5	9	1	15
Unknown	12	9	4	25	10	1	5	16
<b>Total</b>	<b>186</b>	<b>101</b>	<b>48</b>	<b>335</b>	<b>186</b>	<b>126</b>	<b>54</b>	<b>366</b>

Table C8: CDC participants by prior service status - percentages

	April-June				July-September			
	CDCL	CDCH	CDCHD	Total	CDCL	CDCH	CDCHD	Total
Did not receive services	30%	18%	17%	24%	24%	27%	15%	24%
Received CACP	37%	24%	13%	29%	33%	22%	20%	28%
Received EACH	1%	13%	10%	6%	1%	17%	2%	7%
Received EACHD	0%	1%	25%	4%	0%	1%	22%	4%
Received HACC or other community care	24%	30%	21%	25%	33%	25%	30%	30%
Other	3%	6%	6%	4%	3%	7%	2%	4%
Unknown	6%	9%	8%	7%	5%	1%	9%	4%
<b>Total</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>

*Table C9: CDC participants who exited, by reason for exit*

	April-June				July-Sept			
	CDCL	CDCH	CDCHD	Total	CDCL	CDCH	CDCHD	Total
Died	1	6	1	8	1	6	1	8
Moved to another town/city/state	1			1				
Moved to residential aged care	6	6	5	17	13	6	4	23
Moved to standard (non-CDC) package	4		2	6	5	2	1	8
No longer needed package	2			2				
Other	1	3		4	2	2		4
Grand Total	15	15	8	38	22	14	5	41

*Table C10: CDC participants who exited, by reason for exit – percentages*

	April-June				July-Sept			
	CDCL	CDCH	CDCHD	Total	CDCL	CDCH	CDCHD	Total
Died	7%	40%	13%	21%	5%	43%	20%	20%
Moved to another town/city/state	7%	0%	0%	3%	0%	0%	0%	0%
Moved to residential aged care	40%	40%	63%	45%	59%	43%	80%	56%
Moved to standard (non-CDC) package	27%	0%	25%	16%	23%	14%	20%	20%
No longer needed package	13%	0%	0%	5%	0%	0%	0%	0%
Other	7%	20%	0%	11%	9%	14%	0%	10%
Total	100%	100%	100%	100%	100%	100%	100%	100%

*Table C11: Expenditure on in-house and brokered supports*

	April-June			July-September		
	In-house	Brokered	Total	In-house	Brokered	Total
CDCL	\$172,033	\$70,643	\$242,676	\$157,703	\$87,891	\$245,594
CDCH	\$266,732	\$12,8890	\$395,622	\$235,956	\$223,811	\$459,767
CDCHD	\$94,010	\$119,776	\$213,786	\$115,142	\$118,763	\$233,905
<b>Total</b>	<b>\$532,775</b>	<b>\$319,309</b>	<b>\$852,084</b>	<b>\$508,801</b>	<b>\$430,465</b>	<b>\$939,266</b>

note excludes expenditure on case management and administration

*Table C12: Expenditure on in-house and brokered supports – percentage splits*

	April-June		July-September	
	In-house	Brokered	In-house	Brokered
CDCL	71%	29%	64%	36%
CDCH	67%	33%	51%	49%
CDCHD	44%	56%	53%	47%
<b>Total</b>	<b>63%</b>	<b>37%</b>	<b>55%</b>	<b>45%</b>

note excludes expenditure on case management and administration

Table C13: Top 10 service types accessed, by hours – CDCL

April-June			July-September		
	Hours	% of total hours		Hours	% of total hours
1 Domestic assistance	2679	32%	1 Domestic assistance	2088	17%
2 Activities of daily living	1633	20%	2 Activities of daily living	1998	16%
3 Social support	1159	14%	3 Centre based day care	1232	10%
4 Centre based day care	625	8%	4 Social support	973	8%
5 Informal services	625	8%	5 Emotional support	536	4%
6 Nutrition, hydration and meal preparation	416	5%	6 Nutrition, hydration and meal preparation	483	4%
7 Leisure, interests and activities	275	3%	7 Informal services	251	2%
8 Home maintenance	230	3%	8 Home maintenance	242	2%
9 Emotional support	122	1%	9 Leisure, interests and activities	202	2%
10 Nursing care	96	1%	10 Support for care recipients with cognitive impairment	165	1%
<b>Total hours*</b>	<b>8326</b>		<b>Total hours*</b>	<b>12547</b>	

\*Excludes supports that were not measured in hours, and on-call access

Table C14: Top 10 service types accessed – by number of participants accessing each service type, CDCL

April-June		No. of participants	% of total participants	July-September		No. of participants	% of total participants
1	Domestic assistance	147	79%	1	Domestic assistance	119	64%
2	Activities of daily living	88	47%	2	Activities of daily living	84	45%
3	Social support	69	37%	3	Social support	56	30%
4	On-call access	41	22%	4	Nutrition, hydration and meal preparation	42	23%
5	Nutrition, hydration and meal preparation	36	19%	5	Emotional support	33	18%
6	Leisure, interests and activities	32	17%	6	Home maintenance	33	18%
7	Home maintenance	32	17%	7	Leisure, interests and activities	22	12%
8	Emotional support	32	17%	8	Home safety	16	9%
9	Home safety	28	15%	9	Mobility and dexterity	16	9%
10	Allied health	18	10%	10	Informal services	14	8%
Total participants		186		Total participants		186	

Table C15: Top 10 services types accessed – by expenditure, CDCL

April-June			July-September		
	Expenditure	% of total expenditure		Expenditure	% of total expenditure
1 Domestic assistance	\$82,902	34%	1 Domestic assistance	\$70,822	29%
2 Activities of daily living	\$52,960	22%	2 Activities of daily living	\$61,709	25%
3 Social support	\$39,067	16%	3 Social support	\$28,245	12%
4 Nutrition, hydration and meal preparation	\$15,694	6%	4 Nutrition, hydration and meal preparation	\$17,435	7%
5 Home maintenance	\$9,525	4%	5 Home maintenance	\$12,071	5%
6 Leisure, interests and activities	\$8,961	4%	6 Transport	\$11,257	5%
7 Mobility and dexterity	\$4,404	2%	7 Support for care recipients with cognitive impairment	\$7,830	3%
8 Centre based day care	\$4,212	2%	8 Leisure, interests and activities	\$7,371	3%
9 Equipment	\$4,099	2%	9 Equipment	\$4,726	2%
10 Emotional support	\$3,914	2%	10 Emotional support	\$3,806	2%
<b>Total expenditure*</b>	<b>\$242,676</b>		<b>Total expenditure*</b>	<b>\$245,594</b>	

Table C16: Top 10 services types accessed, by hours – CDCH

April-June			July-September		
	Hours	% of total hours		Hours	% of total hours
1 Activities of daily living	4095	34%	1 Activities of daily living	4818	32%
2 Domestic assistance	1632	14%	2 Domestic assistance	1792	12%
3 Leisure, interests and activities	1574	13%	3 Social support	1601	11%
4 Social support	902	8%	4 Nutrition, hydration and meal preparation	975	6%
5 Nutrition, hydration and meal preparation	809	7%	5 Support for care recipients with cognitive impairment	784	5%
6 Continence management	435	4%	6 Centre based day care	453	3%
7 Mobility and dexterity	397	3%	7 Continence management	430	3%
8 Nursing care	334	3%	8 Nursing care	365	2%
9 Informal services	269	2%	9 Leisure, interests and activities	337	2%
10 Centre based day care	254	2%	10 Emotional support	335	2%
<b>Total hours*</b>	<b>11930</b>		<b>Total hours*</b>	<b>15075</b>	

\*Excludes supports that were not measured in hours, and on-call access

Table C17: Top 10 service types accessed – by number of participants accessing each service type, CDCH

April-June		No of participants	% of total participants	July-September		No of participants	% of total participants
1	Activities of daily living	75	74%	1	Activities of daily living	94	75%
2	Domestic assistance	69	68%	2	Domestic assistance	66	52%
3	Nursing care	44	44%	3	Social support	49	39%
4	Social support	37	37%	4	Nursing care	39	31%
5	On-call access	36	36%	5	Nutrition, hydration and meal preparation	36	29%
6	Nutrition, hydration and meal preparation	36	36%	6	Clinical care	32	25%
7	Continence management	31	31%	7	Allied health	30	24%
8	Clinical care	30	30%	8	Emotional support	22	17%
9	Leisure, interests and activities	27	27%	9	Continence management	22	17%
10	Allied health	25	25%	10	Management of skin integrity	21	17%
<b>Total participants</b>		<b>101</b>		<b>Total participants</b>		<b>126</b>	

Table C18: Top 10 service types accessed – by expenditure, CDCH

April-June		Expenditure	% of total expenditure	July-September		Expenditure	% of total expenditure
1	Activities of daily living	\$125,528	32%	1	Activities of daily living	\$163,499	36%
2	Leisure, interests and activities	\$62,352	16%	2	Social support	\$60,931	13%
3	Domestic assistance	\$45,540	12%	3	Domestic assistance	\$52,296	11%
4	Social support	\$23,614	6%	4	Nutrition, hydration and meal preparation	\$31,760	7%
5	Equipment	\$19,468	5%	5	Nursing care	\$20,081	4%
6	Nutrition, hydration and meal preparation	\$16,370	4%	6	Continence management	\$17,630	4%
7	Informal services	\$13,093	3%	7	Leisure, interests and activities	\$15,713	3%
8	Home modification	\$13,046	3%	8	Equipment	\$14,921	3%
9	Continence management	\$12,274	3%	9	Support for care recipients with cognitive impairment	\$14,547	3%
10	Mobility and dexterity	\$12,175	3%	10	Clinical care	\$14,479	3%
Total expenditure*		\$395,622		Total expenditure*		\$459,767	

\*excludes expenditure on case planning and management, and includes expenditure on service types that do not feature on the top 10

Table C19: Top 10 services types accessed – by hours, CDCHD

April-June			July-September		
	Hours	% of total hours		Hours	% of total hours
1 Activities of daily living	1657	29%	1 Activities of daily living	2222	29%
2 Leisure, interests and activities	1034	18%	2 Centre based day care	1096	14%
3 Domestic assistance	639	11%	3 Social support	845	11%
4 Centre based day care	536	9%	4 Domestic assistance	670	9%
5 Social support	305	5%	5 Informal services	661	9%
6 Nutrition, hydration and meal preparation	287	5%	6 Leisure, interests and activities	575	8%
7 Support for care recipients with cognitive impairment	276	5%	7 Support for care recipients with cognitive impairment	371	5%
8 Nursing care	168	3%	8 Nutrition, hydration and meal preparation	367	5%
9 Home safety	125	2%	9 Emotional support	335	4%
10 Home modification	121	2%	10 Continence management	112	1%
<b>Total hours*</b>	<b>5645</b>		<b>Total hours*</b>	<b>7627</b>	

\*Excludes supports that were not measured in hours, and on-call access

Table C20: Top 10 service types accessed – by number of participants accessing each service type, CDCHD

April-June		No of participants	% of total participants	July-September		No of participants	% of total participants
1	Activities of daily living	32	67%	1	Activities of daily living	28	52%
2	Domestic assistance	31	65%	2	Domestic assistance	12	22%
3	Leisure, interests and activities	18	38%	3	Nursing care	12	22%
4	Nutrition, hydration and meal preparation	17	35%	4	Social support	11	20%
5	Clinical care	15	31%	5	Clinical care	11	20%
6	Social support	14	29%	6	Allied health	10	19%
7	Nursing care	13	27%	7	Support for care recipients with cognitive impairment	10	19%
8	Support for care recipients with cognitive impairment	13	27%	8	Continence management	9	17%
9	Emotional support	11	23%	9	Emotional support	8	15%
10	Allied health	10	21%	10	Leisure, interests and activities	8	15%
<b>Total participants</b>		<b>48</b>		<b>Total participants</b>		<b>54</b>	

Table C21: Top 10 service types accessed – by expenditure, CDCHD

April-June		Expenditure	% of total expenditure	July-September		Expenditure	% of total expenditure
1	Activities of daily living	\$50,474	24%	1	Activities of daily living	\$80,948	32%
2	Leisure, interests and activities	\$41,605	19%	2	Support for care recipients with cognitive impairment	\$42,451	17%
3	Domestic assistance	\$21,568	10%	3	Social support	\$32,786	13%
4	Social support	\$14,501	7%	4	Leisure, interests and activities	\$27,305	11%
5	Equipment	\$13,343	6%	5	Domestic assistance	\$18,876	7%
6	Support for care recipients with cognitive impairment	\$12,340	6%	6	Continence management	\$8,860	3%
7	Nutrition, hydration and meal preparation	\$11,116	5%	7	Nutrition, hydration and meal preparation	\$7,515	3%
8	Centre based day care	\$10,824	5%	8	Centre based day care	\$5,141	2%
9	Home modification	\$10,245	5%	9	Informal services	\$5,006	2%
10	Continence management	\$5,896	3%	10	Allied health	\$4,872	2%
Total expenditure*		\$213,786		Total expenditure*		\$253,515	

Table C22: Average hourly rates charged - CDC

Service type	April-June	July-Sept
Activities of daily living	\$31.00	\$33.87
Allied health	\$53.87	\$77.87
Centre based day care	\$12.57	\$4.92
Clinical care	\$42.96	\$56.28
Continence management	\$36.98	\$53.86
Domestic assistance	\$30.31	\$31.87
Emotional support	\$34.64	\$15.42
Home maintenance	\$40.03	\$46.66
Informal services	\$17.87	\$11.55
Leisure, interests and activities	\$39.17	\$41.99
Management of skin integrity	\$19.33	\$32.24
Mobility and dexterity	\$35.75	\$35.06
Nursing care	\$20.74	\$48.00
Nutrition, hydration and meal preparation	\$28.56	\$26.65
Social support	\$32.62	\$35.67
Support for care recipients with cognitive impairment	\$45.38	\$50.49
Therapy services	\$42.01	\$44.85

Table C23: Administration and case planning and coordination – CDC

	April-June				July-Sept			
	CDCL	CDCH	CDCHD	Total	CDCL	CDCH	CDCHD	Total
<i>Number of participants where administration and/or case planning and management was charged</i>								
Administration	154	79	33	266	157	107	47	311
Care planning and management	174	82	35	291	157	105	44	306
<i>Proportion of participants where administration and/or case planning and management was charged</i>								
Administration	83%	78%	69%	79%	84%	85%	87%	85%
Care planning and management	94%	81%	73%	87%	84%	83%	81%	84%
<i>Total number of hours reported</i>								
Administration	3526	1515	423	5463	1479	1304	793	3576
Care planning and management	1855	1349	499	3703	1672	1463	693	3828
<i>Average number of hours per participant (where admin and/or care planning and management is recorded)</i>								
Administration	22.9	19.2	12.8	20.5	9.4	12.2	16.9	11.5
Care planning and management	10.7	16.5	14.3	12.7	10.6	13.9	15.8	12.5
Combined	33.6	35.6	27.1	33.3	20.1	26.1	32.6	24.0
<i>Total expenditure</i>								
Administration	\$50,098	\$45,326	\$37,283	\$132,707	\$63,180	\$74,236	\$41,985	\$179,401
Care planning and management	\$58,840	\$63,031	\$27,518	\$149,389	\$51,938	\$59,133	\$24,658	\$135,729
<i>Average expenditure per participant (per quarter)</i>								
Administration	\$355	\$687	\$1,097	\$551	\$402	\$694	\$893	\$577
Care planning and management	\$403	\$1,033	\$809	\$620	\$331	\$563	\$560	\$444
Combined	\$758	\$1,720	\$1,906	\$1,171	\$733	\$1,257	\$1,454	\$1,020

	April-June				July-Sept			
	CDCL	CDCH	CDCHD	Total	CDCL	CDCH	CDCHD	Total
<i>Average expenditure per participant (annualised)</i>								
Administration	\$1,421	\$2,747	\$4,386	\$2,203	\$1,610	\$2,775	\$3,573	\$2,307
Care planning and management	\$1,612	\$4,133	\$3,237	\$2,479	\$1,323	\$2,253	\$2,242	\$1,774
Combined	\$3,033	\$6,880	\$7,624	\$4,682	\$2,933	\$5,028	\$5,815	\$4,082
<i>Proportion of reported package expenditure</i>								
Administration	14%	9%	13%	12%	17%	12%	13%	14%
Care planning and management	17%	13%	10%	13%	14%	10%	8%	11%
Combined	31%	21%	23%	25%	32%	22%	21%	25%
Supports	69%	79%	77%	75%	68%	78%	79%	75%

Table C24: Set-up costs reported by CDC providers – 2010-11

	Total costs reported			Average cost per package allocated*		
	Staffing	Non-staffing	Total	Staffing	Non-staffing	Total
Planning	\$244,995	\$12,321	\$257,316	\$556	\$28	\$583
Development or modification of systems (eg IT systems) and processes	\$164,234	\$19,860	\$184,094	\$372	\$45	\$417
Development of information and other resources	\$106,810	\$11,638	\$118,448	\$242	\$26	\$269
Participant recruitment	\$73,603	\$4,622	\$78,225	\$167	\$10	\$177
Training and skills development	\$120,067	\$9,007	\$129,074	\$272	\$20	\$293
Other	\$161,581	\$74,669	\$236,249	\$366	\$169	\$536
<b>Total</b>	<b>\$871,289</b>	<b>\$132,116</b>	<b>\$1,003,406</b>	<b>\$1,976</b>	<b>\$300</b>	<b>\$2,275</b>

\*Average cost per package is based on 441 packages, which is the number of packages allocated to those providers who submitted data as part of the April-June provider data collection. Note not all of these packages had been allocated to participants.

Table C25: Ongoing costs reported by CDC providers

	Total costs reported			Average cost per package allocated		
	Staffing	Non-staffing	Total	Staffing	Non-staffing	Total
<i>Management and administration</i>						
Management	\$88,486	\$17,361	\$105,847	\$1,011	\$198	\$1,210
Administration	\$51,195	\$10,017	\$61,212	\$585	\$114	\$700
Finance and IT support	\$56,230	\$12,048	\$68,278	\$643	\$138	\$780
Other	\$21,669	\$17,080	\$38,749	\$248	\$195	\$443
Unspecified	\$47,767	\$690	\$48,457	\$546	\$8	\$554
<i>Participant selection</i>	\$27,695	\$1,794	\$29,489	\$317	\$21	\$337
<i>Case planning and coordination</i>	\$224,412	\$11,149	\$235,561	\$2,565	\$127	\$2,692
<b>Total</b>	<b>\$517,455</b>	<b>\$70,139</b>	<b>\$587,593</b>	<b>\$5,914</b>	<b>\$802</b>	<b>\$6,715</b>
<b>Total (excl case planning and coordination)</b>	<b>\$293,043</b>	<b>\$58,990</b>	<b>\$352,032</b>	<b>\$3,349</b>	<b>\$674</b>	<b>\$4,023</b>

Based on data provided by 35 organisations, encompassing 350 packages allocated to participants

Source: 2<sup>nd</sup> CDC provider data collection

Table C26: Time (hours) spent on participant selection, planning and coordination - CDC

	CDCL	CACP	CDCH	EACH	CDCHD	EACHD
Time spent providing information to a potential CDC participant – <i>per potential participant (hours)</i>	2.4		2.5		2.8	
Time spent undertaking care planning– <i>per participant (hours)</i>	2.9	2.1	3.9	2.5	4.2	2.7
Time spent managing and coordinating package– <i>per participant per week (hours)</i>	1.4	1.0	2.4	1.8	2.6	2.1
Time spent conducting formal review – <i>per participant per review undertaken (every 3-6 months) (hours)</i>	1.3	1.1	1.9	1.6	2.0	1.6

### C.3 Consumer-directed respite care packages – participants, services and expenditure

The following tables relate to the characteristics of CDRC participants and the services they use, as reported by CDRC providers as part of the April-June and July-September provider data collections undertaken as part of this evaluation.

*Table C27: CDRC participants by age*

	April-June	July-Sept	April-June	July-Sept	NRCP 2011-Q1
0-39	8	2	5%	1%	10%
40-49	17	21	10%	11%	14%
50-54	22	18	13%	9%	10%
55-59	28	38	16%	19%	12%
60-64	23	30	13%	15%	13%
65-69	26	25	15%	13%	10%
70-74	15	22	9%	11%	9%
75-79	24	21	14%	11%	8%
80-84	6	14	3%	7%	7%
85-89	3	2	2%	1%	4%
90+	0	2	0%	1%	1%
<b>Total</b>	<b>172</b>	<b>195</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>

Table C28: CDRC participants by special needs group status

	April-June	July-Sept	April-June	July-Sept	NRCP 2011-Q1
ATSI	16	6	9%	3%	3%
Financially/socially disadvantaged	61	60	35%	31%	
Homeless (or at risk of)	3	1	2%	1%	
Live in a rural/remote area	35	41	20%	21%	
CALD	24	32	14%	16%	6%
Veteran	2	2	1%	1%	
Care leaver		1	0%	1%	

Table C29: Reason for exit - CDRC

Reason for exit	April-June	July-Sept
Care recipient died	11	1
Moved to another town/city/state	1	
Care recipient moved to residential aged care	12	11
Care recipient moved to standard (non-CDRC) package	15	
No longer needed package	9	
Other	27	
<b>Total exits</b>	<b>75</b>	<b>12</b>
<i>Proportion of participants exiting</i>	<i>44%</i>	<i>6%</i>

*Table C30: Participant living arrangements - CDRC*

	April-June	July-Sept	April-June	July-Sept
Does not live with the person they care for	32	25	19%	13%
Lives with the person they care for	139	170	81%	87%
Other	1		1%	0%
<b>Total</b>	<b>172</b>	<b>195</b>	<b>100%</b>	<b>100%</b>

*Table C31: Service status prior to commencing CDRC*

	April-June	July-Sept	April-June	July-Sept
Received HACC or other community care	61	102	35%	52%
Received NRCP services	52	32	30%	16%
Did not receive services	51	53	30%	27%
Other/unknown	8	8	5%	4%
<b>Total</b>	<b>172</b>	<b>195</b>	<b>100%</b>	<b>100%</b>

Table C32: Top 10 services types accessed – by hours, CDRC

April-June			July-September		
	Hours	% of total hours		Hours	% of total hours
1 Commonwealth funded residential respite	10967	48%	1 Commonwealth funded residential respite	6714	43%
2 In home respite	2771	12%	2 Community residential respite	1888	12%
3 Regular respite care	1834	8%	3 Centre based day care	1548	10%
4 Individualised respite	1308	6%	4 In home respite	1281	8%
5 Other residential respite	872	4%	5 Social support	929	6%
6 Community respite	711	3%	6 Individualised respite	892	6%
7 Community residential respite	669	3%	7 Regular respite care	786	5%
8 Personal care	454	2%	8 Assessment	438	3%
9 Centre based day care	454	2%	9 Liaison/advice/support/ counselling	375	2%
10 Social support	414	2%	10 Information provision	346	2%

\*Excludes supports that were not measured in hours

Table C33: Top 10 service types accessed – by number of participants accessing each service type, CDRC

April-June			July-September		
	No of participants	% of total participants		No of participants	% of total participants
1 Liaison/advice/support/ counselling	125	73%	1 Assessment	154	79%
2 Information provision	115	67%	2 Information provision	122	63%
3 Assessment	83	48%	3 Liaison/advice/support/ counselling	121	62%
4 In home respite	75	44%	4 In home respite	63	32%
5 Regular respite care	36	21%	5 Individualised respite	31	16%
6 Transport	33	19%	6 Regular respite care	23	12%
7 Commonwealth funded residential respite	32	19%	7 Domestic assistance	21	11%
8 Domestic assistance	30	17%	8 Commonwealth funded residential respite	18	9%
9 Individualised respite	29	17%	9 Social support	14	7%
10 Education/training	26	15%	10 Community residential respite	12	6%

Table C34: Top 10 service types accessed – by expenditure, CDRC

April-June				July-September			
		Expenditure	% of total expenditure			Expenditure	% of total expenditure
1	In home respite	104682	31%	1	In home respite	44053	23%
2	Regular respite care	31190	9%	2	Regular respite care	26410	14%
3	Individualised respite	25496	8%	3	Individualised respite	14038	7%
4	Commonwealth funded residential respite	22740	7%	4	Commonwealth funded residential respite	12528	7%
5	Provision of goods and equipment	22689	7%	5	Assessment	11443	6%
6	Personal care	18560	5%	6	Liaison/advice/support/ counselling	10791	6%
7	Community respite	14784	4%	7	Provision of goods and equipment	9763	5%
8	Home maintenance	13051	4%	8	Community residential respite	9595	5%
9	Domestic assistance	12511	4%	9	Social support	9247	5%
10	Home modification	11943	4%	10	Information provision	9025	5%

Table C35: Average hourly rates charged - CDRC

Service type	April-June	July-Sept
Assessment	\$24.41	\$26.13
Information provision	\$24.88	\$26.12
Liaison/advice/support/ counselling	\$25.71	\$28.81
Education/training	\$15.76	\$24.00
Commonwealth funded residential respite	\$2.07	\$1.87
Community residential respite	\$3.48	\$5.08
Community respite	\$20.79	\$4.29
Emergency respite care	\$40.20	\$44.00
In home respite	\$37.78	\$34.39
Individualised respite	\$19.49	\$15.74
Other residential respite	\$2.19	\$75.00
Regular respite care	\$17.01	\$33.60
Centre based day care	\$6.88	\$2.16
Social support	\$19.60	\$9.95
Personal care	\$40.88	\$52.17
Domestic assistance	\$38.73	\$34.69
Nursing care	\$61.38	
Allied health care	\$91.14	\$67.55
Home maintenance	\$78.62	\$106.26
Other	\$29.00	\$23.15

Table C36: Case management and coordination charges - CDRC

	April-June	July-Sept
Number of participants receiving case management and coordination	151	175
Number of hours of case planning and management	1305	1090
<i>Average number of hours of case planning and management per participant</i>	8.6	6.2
<i>Total expenditure</i>		
Case management and coordination	\$32,394	\$30,062
Supports	\$433,8683	\$189,658
<b>Total reported expenditure (excluding administration)</b>	<b>\$371,077</b>	<b>\$219,720</b>
<i>Average expenditure— case management and coordination</i>	<i>\$284</i>	<i>\$237</i>
<i>Average expenditure per participant (annualised)</i>	<i>\$1137</i>	<i>\$947</i>
<i>Proportion of reported package expenditure</i>		
Case management and coordination	9%	14%
Supports	91%	86%

Table C37: CDRC package expenditure - In-house and brokered services

	April-June			July-September		
	In-house	Brokered	Total	In-house	Brokered	Total
Expenditure	\$77,738	\$260,945	\$338,683	\$65,060	\$124,598	\$189,658
% of total	23%	77%	100%	34%	66%	100%

note excludes expenditure on case management and administration

Table C38: Time spent on initiation, planning and coordination (hours) – CDRC

	Hours - CDRC	Hours - NRCP
Time spent providing information to a potential CDRC participant – <i>per potential participant (hours)</i>	2.5	
Time spent undertaking care planning– <i>per participant (hours)</i>	3.0	1.8
Time spent managing and coordinating package– <i>per participant per week (hours)</i>	1.8	1.3
Time spent conducting formal review – <i>per participant per review undertaken (every 3-6 months) (hours)</i>	2.3	1.1

Table C39: Set-up costs reported by CDRC providers – 2010-11

	Total costs reported			Average cost per package allocated*		
	Staffing	Non-staffing	Total	Staffing	Non-staffing	Total
Planning	\$41,767	\$820	\$42,587	\$246	\$5	\$251
Development or modification of systems (eg IT systems) and processes	\$11,996	\$3,414	\$15,410	\$71	\$20	\$91
Development of information and other resources	\$21,496	\$3,444	\$24,940	\$126	\$20	\$147
Participant recruitment	\$28,833	\$1,978	\$30,811	\$170	\$12	\$181
Training and skills development	\$13,981	\$8,474	\$22,455	\$82	\$50	\$132
Other	\$41,219	\$9,278	\$50,497	\$242	\$55	\$297
<b>Total</b>	<b>\$159,292</b>	<b>\$27,408</b>	<b>\$186,700</b>	<b>\$937</b>	<b>\$161</b>	<b>\$1,098</b>

\*Average cost per package is based on 441 packages, which is the number of packages allocated to those providers who submitted data as part of the April-June provider data collection. Note not all of these packages had been allocated to participants.

Source: April-June provider data collection

Table C40: Ongoing costs reported by CDRC providers

	Total costs reported			Average cost per package allocated		
	Staffing	Non-staffing	Total	Staffing	Non-staffing	Total
<i>Management and administration</i>						
Management	\$13,328	\$76	\$13,404	\$284	\$2	\$285
Administration	\$12,284	\$2,644	\$14,928	\$261	\$56	\$318
Finance and IT support	\$9,482	\$3,534	\$13,016	\$202	\$75	\$277
Other	\$20,569	\$5,528	\$26,097	\$438	\$118	\$555
Unspecified	\$600	\$0	\$600	\$13	\$0	\$13
<i>Participant selection</i>	\$17,577	\$1,010	\$18,587	\$374	\$21	\$395
<i>Case planning and coordination</i>	\$40,062	\$1,350	\$41,412	\$852	\$29	\$881
<b>Total</b>	<b>\$113,902</b>	<b>\$14,142</b>	<b>\$128,044</b>	<b>\$2,423</b>	<b>\$301</b>	<b>\$2,724</b>
<i>Total (excl case planning and coordination)</i>	<i>\$73,840</i>	<i>\$12,792</i>	<i>\$86,632</i>	<i>\$1,571</i>	<i>\$272</i>	<i>\$1,843</i>

Based on data provided by 16 organisations, encompassing 188 CDRC packages allocated to participants

Source: 2<sup>nd</sup> CDRC provider data collection

## D. CDC and CDRC providers interviewed

### D.1 Participant interviews

The characteristics of the CDC participant and carer interviews conducted as part of the evaluation are outlined below:

	Participant	Carer of participant	Total
CDCL	23	3	26
CDCH	8	10	18
CDCHD	1*	6	7
<b>Total</b>	<b>32</b>	<b>19</b>	<b>51</b>
Person living with dementia	2	9	11
Indigenous	3	1	4
CALD	5	2	7
Homeless	4	1	5

\*interview with participant and their carer

The characteristics of the CDRC participant interviews conducted as part of the evaluation are outlined below:

	Participant (carer)
<b>Total</b>	<b>27</b>
Person being cared for*	3
Caring for a person living with dementia	13
Indigenous	1
CALD	6

\*interview with carer and person being cared for

## D.2 CDC and CDRC providers interviews

The following CDC providers were interviewed as part of the evaluation:

1	Illawarra Retirement Trust (ACT)	ACT
2	Uniting Church in Australia Property Trust (NSW)	NSW
3	The Benevolent Society	NSW
4	Catholic Healthcare	NSW
5	Mid North Coast Community Options	NSW
6	Golden Glow	NT
7	Ozcare	QLD
8	Uniting Church in Australia Property Trust (Qld)	QLD
9	Home Support Services	QLD
10	Alwyndor Aged Care	SA
11	Resthaven	SA
12	South Eastern Community Care	TAS
13	BaptCare	VIC
14	Uniting Church in Australia Property Trust (Victoria)	VIC
15	Wintringham	VIC
16	Almana Living	WA

The following CDRC providers were interviewed as part of the evaluation:

1	The Benevolent Society	NSW
2	Catholic Healthcare	NSW
3	Intereach NSW	NSW
4	Carers NT	NT
5	Uniting Church in Australia Property Trust (Qld)	QLD
6	UnitingCare Wesley Adelaide	SA
7	Community Based Support South	TAS
8	Bendigo Health Care Group	VIC
9	Independent Living Centre of WA	WA
10	Silver Chain Nursing Association	WA