



**Australian Government**

**Australian Institute of  
Health and Welfare**

*Better information and statistics  
for better health and wellbeing*

# **Carers National Data Repository scoping study**

## **Final report**

**August 2009**

Australian Institute of Health and Welfare  
Canberra

Cat. no. AGE 59

**The Australian Institute of Health and Welfare is Australia's national health and welfare statistics and information agency. The Institute's mission is *better information and statistics for better health and wellbeing.***

© Australian Institute of Health and Welfare 2009

This work is copyright. Apart from any use as permitted under the *Copyright Act 1968*, no part may be reproduced without prior written permission from the Australian Institute of Health and Welfare. Requests and enquiries concerning reproduction and rights should be directed to the Head, Media and Communications Unit, Australian Institute of Health and Welfare, GPO Box 570, Canberra ACT 2601.

A complete list of the Institute's publications is available from the Institute's website <[www.aihw.gov.au](http://www.aihw.gov.au)>.

ISBN 978 1 74024 946 1

### **Suggested citation**

Australian Institute of Health and Welfare 2009. Carers National Data Repository scoping study: final report. Cat. no. AGE 59. Canberra: AIHW.

### **Australian Institute of Health and Welfare**

Board Chair

Hon. Peter Collins, AM, QC

Director

Penny Allbon

Any enquiries about or comments on this publication should be directed to:

Head, Ageing and Aged Care Unit  
Australian Institute of Health and Welfare  
GPO Box 570  
Canberra ACT 2601  
Phone: (02) 6244 1108  
Email: [agedcare@aihw.gov.au](mailto:agedcare@aihw.gov.au)

Published by the Australian Institute of Health and Welfare

**Please note that there is the potential for minor revisions of data in this report. Please check the online version at <[www.aihw.gov.au](http://www.aihw.gov.au)> for any amendments.**

# Contents

<b>Acknowledgments</b> .....	<b>iv</b>
<b>Abbreviations</b> .....	<b>v</b>
<b>Summary</b> .....	<b>vi</b>
<b>1 Background</b> .....	<b>1</b>
1.1 The scoping study .....	1
<b>2 Key research and policy issues</b> .....	<b>3</b>
2.1 Scan of recent literature.....	3
2.2 Stakeholder consultations .....	5
<b>3 Scope and feasibility of possible CNDR</b> .....	<b>9</b>
3.1 Sources of carer data.....	9
3.2 Data issues.....	9
<b>4 Possible models for a CNDR</b> .....	<b>13</b>
4.1 Metadata repository/ data portal/ data directory.....	13
4.2 Decentralised virtual hub .....	15
4.3 Centralised physical repository .....	16
<b>5 Case study: exploring the use of respite care using multiple data sets</b> .....	<b>18</b>
5.1 How many carers use respite care services? .....	19
5.2 Source of respite care services.....	23
5.3 Why is respite care not being used? .....	29
5.4 The case study and CNDR models.....	33
<b>6 Conclusions and future directions</b> .....	<b>35</b>
6.1 Usefulness of a CNDR.....	35
6.2 Scope of CNDR.....	35
6.3 Feasibility of CNDR.....	36
6.4 Future directions .....	36
<b>Appendix 1: Data mapping</b> .....	<b>38</b>
<b>Appendix 2: Review of current provisions and policies</b> .....	<b>48</b>
<b>References</b> .....	<b>59</b>

# Acknowledgments

This report was principally authored by Joanna Gilham and Ann Peut of the Ageing and Aged Care Unit at the Australian Institute of Health and Welfare (AIHW), with significant contributions by Catherine Runge. Evon Bowler prepared the indicative data analysis. Helpful referee comments were made by Cathy Hales from the Functioning and Disability Unit and Fadwa Al-yaman.

The Australian Government Department of Health and Ageing provided funding for this project.

The authors thank stakeholders who participated in the project for their generous support, time and critical comments on the draft report. Stakeholder organisations consulted for this project include Carers Australia, Alzheimer's Australia, Centrelink, the Australian Bureau of Statistics (ABS), the Australian Government Departments of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), Veterans' Affairs (DVA), and Health and Ageing (DoHA).

# Abbreviations

ABS	Australian Bureau of Statistics
ACAP	Aged Care Assessment Program
ACCMIS	Aged and Community Care Management Information System
AIHW	Australian Institute of Health and Welfare
CA	Carer Allowance
CACP	Community Aged Care Packages
CALD	Culturally and linguistically diverse
CCC	Community Care Census
CNDR	Carers National Data Repository
CP	Carer Payment
CSTDA	Commonwealth State/Territory Disability Agreement
DoHA	Department of Health and Ageing
DVA	Department of Veterans' Affairs
EACH	Extended Aged Care at Home
EACH-D	Extended Aged Care at Home-Dementia
FaHCSIA	Department of Families, Housing, Community Services and Indigenous Affairs
GSS	General Social Survey
HACC	Home and Community Care
HES	Household Expenditure Survey
MDS	Minimum Data Set
METeOR	Metadata Online Repository
MPHS	Multi-Purpose Household Survey
NHS	National Health Survey
NCSIMG	National Community Services Information Management Group
NRCP	National Respite for Carers Program
PIAC	Pathways in Aged Care
SEARS	Survey of Employment Arrangements, Retirement and Superannuation
SDAC	Survey of Disability, Ageing and Carers
SIH	Survey of Income and Housing
SLK	Statistical Linkage Key
TOCC	Taskforce on Care Costs
TUS	Time Use Survey
VHC	Veterans' Home Care

# Summary

The Department of Health and Ageing (DoHA) commissioned the Australian Institute of Health and Welfare (AIHW) to undertake a study to investigate and document the scope, feasibility and usefulness of setting up a Carers National Data Repository (CNDR). The CNDR is conceived as a way of improving the evidence available about carers, using existing data. This would mitigate issues arising from scattered evidence by bringing data together, standardising metadata and analysing data in more integrated ways (including through the use of data linkage) to inform important policy and research issues.

Support in principle for a CNDR was received from the majority of stakeholders, and was strongest from advocacy groups. This was primarily based on recognition of a strong need for better evidence which would facilitate improved carer services and support arrangements. Underpinning this was acknowledgment of a need for wider data access and research relating to carers. However, data custodians expressed concerns about privacy, data quality and access, technical expertise and issues such as the physical format and transmission of data.

Three repository models were proposed by and discussed with stakeholders during the consultation process. These included a repository of metadata only, without storage of data; a virtual 'hub' from which web-based access can be gained to data held by data custodians; and a physical data repository, with data collections or copies centrally located, incorporating a program of data development and analysis.

While the metadata directory model would receive support from all stakeholders, including most data custodians, the benefits of establishing a repository of this type would be limited, particularly in view of the potential resources required to establish and maintain it. It is not certain that either of the other models for the CNDR would receive sufficient support from data custodians at this time to make them feasible.

A physical CNDR offers the most potential for achieving strong gains in the quality and visibility of evidence about carers, particularly if it incorporates the capacity to develop expertise in data linkage and integrated data analysis. Its feasibility and value should be reviewed in future. The way forward in the short term would appear to lie in:

- a coherent program of regular data analysis and reporting using existing data, including developing Statistical Linkage Key (SLK) capability for carer data across data collections. This work could be considered for inclusion on the work plan of the National Community Services Information Management Group (NCSIMG).
- improving the coverage, quality and consistency of carer data. The NCSIMG strategic plan for 2005–2009 specified that a review of existing collections relating to informal care was a priority for action. With the expiry of the current strategic plan and the development of an updated one, it is important that such a review remains a priority.
- closing some of the gaps in data available to inform key issues through enhancement of existing data collections and potentially developing new data collections with a stronger focus on gathering data from carers about their needs and circumstances.

The renewed emphasis on performance reporting as part of the Council of Australian Governments' reforms will have an impact on data development and reporting over the next few years, including for carer data which features prominently in the new National Disability Agreement. These developments increase the desirability of consistency in carer data items across existing data sets and making maximum use of existing data.

# 1 Background

Unpaid carers perform a vital role in the provision of care to people of all ages with disability. Around 2.6 million Australian carers provided unpaid assistance to people with disability (including age-related conditions) in 2003. The nature of the caring role is varied, depending on factors such as the nature and quantity of care provided, the circumstances and health of the care recipient and the relationship between carer and care recipient. Consequently, data describing carers is conceptually related to data describing the care recipient, and their relationship.

The development of policies and services for carers is currently hampered by the absence of a robust, well-developed evidence base. Data relating to carers is spread across multiple data sources, both administrative and survey based, owned and held by multiple data custodians. This has led to fragmented analyses and, at most, a partial understanding of carer characteristics, needs and service-use patterns.

For example, the Survey of Disability, Ageing and Carers (SDAC) collects information about unmet need, and reports that the top two areas in which carers need additional assistance are financial assistance and respite care. To look more closely at what is occurring in these areas using existing data sets, we need carer-specific payment data held by Centrelink and respite usage data from a number of program data collections held by the Departments of Health and Ageing (DoHA), Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and Veterans' Affairs (DVA).

The Carers' National Data Repository (CNDR) is conceived of as a way towards making improvements to evidence about carers, using existing data. It could mitigate issues arising from scattered data by bringing these together and standardising metadata. The concept of the CNDR involves three aspects: developing a work plan that systematically addresses key questions about the way carers are supported in their role; bringing key data sources together in one place (the repository); and analysing the data in more integrated ways. Potential benefits of a CNDR include greater visibility of data and information about carers, easier access to relevant data and improved capacity to analyse data for policy-relevant purposes. Initially the CNDR's contribution to the evidence base would be limited by the status and constraints of current data sources. However, increased visibility of carer data may provide the impetus to improve the comprehensiveness of existing data, and its quality and consistency across different collections.

## 1.1 The scoping study

The AIHW received funding from DoHA to undertake a scoping study investigating and documenting the scope, feasibility and usefulness of a CNDR. Individual data collections are already held in data repositories, for example, the Home and Community Care (HACC) National Data Repository and the Aged Care Assessment Program (ACAP) National Data Repository. The CNDR is not envisaged as a replacement for such repositories which would continue to serve a role in the collection, quality assurance and storage of data for program management, monitoring and reporting purposes. Other types of existing data warehouses, for example, the Aged and Community Care Management Information System (ACCMIS), will also continue to service portfolio-specific purposes. The CNDR would enable data from different data collections across a range of data collection agencies and portfolios to be brought together.

The scoping study:

- identifies key policy and research issues relevant to carers and those being cared for, and which data in the repository could inform, through a brief literature review and stakeholder consultation
- considers the potential scope of a CNDR. The report identifies some of the major relevant data collections and data elements; investigates issues associated with data collections which might potentially be included in a repository and broadly examines issues of data consistency and quality which currently affect data analyses and consequent usefulness
- undertakes an exploration of existing data from multiple data sources in relation to respite care use to highlight both the possibilities and issues associated with undertaking a more integrated approach to data analysis
- outlines possible models for a repository and the benefits they would deliver and makes some recommendations for possible next steps.

## 2 Key research and policy issues

A scan of the literature was undertaken to identify major research and policy issues relevant to carers. These issues were also discussed with key stakeholders. The purpose in doing this was to establish to what extent existing data sources could be used to examine these issues (either singly or in combination), and further, whether a CNDR could add value to such examination.

### 2.1 Scan of recent literature

Literature from 2004 to mid-2007 on the broad subject of informal care was sourced from social science journals on Proquest<sup>1,2</sup> articles and references in the 'carers' edition of the Family Matters journal (no. 76), position papers from carer advocacy groups and findings from data set reports. The literature scan aimed to identify the key policy and research issues that consistently arose across the literature.

Research on informal care can at times appear fragmented or limited. Berg-Weger and Tebb's interviews with caregiver researchers (Berg-Weger & Tebb 2004) revealed a view that inconsistencies in definitions, measurement and sampling hamper study of the caregiving experience. The researchers supported the need for caregiver research to include greater use of national population samples and studies of role entry and transitions. Hales (2007) also contends that greater use should be made of existing data and states that there is scope for data collections to be improved to explore the interplay between informal and formal care.

Key issues confounding carer research are how carers and the caring relationship are defined, how carers identify themselves and how they are identified in data sets. Barrett's study of 76 carers (Barrett 2005) found that some 'carers' identified with the term 'from the time their family members first began needing care that exceeded the normal demands of their familial role' (p. 45) while others only identified with the term when they were labelled as such by support services.

Cardona and colleagues (Cardona et al. 2006) found similar mindsets in their study of 42 'carers'. Identification with the role of carer was in some cases related to the more specific provision of personal care such as showering, but rarely to describe the relationship between the 'carer' and care recipient. Some participants in Cardona and colleagues' study recognised that identification with the role of carer acted as a means to access services and payments: carers who were receiving the Carer Payment had less difficulty in identifying themselves as carers. The qualifying note to the 2006 ABS Census 'carer' question compels the connection between receipt of Carer Allowance or Carer Payment and identification as a carer, by stating that 'recipients of Carer Allowance or Carer Payment should state that they provided unpaid care'.

The literature scan revealed financial issues, workforce participation, service provision and stress and burden as salient issues for carers. Analysis of the 2003 SDAC (Hales 2007) found that 27% of

- 
1. Since the literature review was completed, the Centre for Health Service Development at the University of Wollongong has released *Effective Caring: a synthesis of the international evidence on carer needs and interventions*. The aims of this report are to identify the needs of carers, identify interventions and to develop a research agenda. The report provides a more comprehensive review of policy, practice and literature than has been undertaken in this study.
  2. The social science database <[www.proquest.com](http://www.proquest.com)> was searched using the terms 'carers', 'caregivers', 'caring' and 'informal care'.

primary carers experienced difficulty in meeting everyday living costs and 23% were incurring extra expenses associated with caring. Carers Australia (2004) notes that caring responsibilities not only restrict a carer's income-earning capacity, but also incur extra costs, such as medications, greater use of electricity, transport costs and special equipment. The Taskforce on Care Costs (TOCC) highlighted in their 2007 report (TOCC 2007) that while CPI increased by 4% in 2006, care costs increased by 10%.

In the SDAC, primary carers indicated that they would like more financial assistance to help them in their caring role. Less than 15% of the total care population access the Carer Allowance (Hughes 2007), while approximately 19% received the Carer Payment in 2003 (Hales 2007). However, over half of carers (56%) had not checked their eligibility for the payment (Hales 2007).

The annual cost borne by carers due to lost opportunities meanwhile was estimated to be more than \$4.9 billion in lost earnings. Access Economics (2005) calculated that the replacement valuation of informal care (resources that would need to be diverted each year from the formal economy to replace the work of informal carers) would be \$30.5 billion.

Financial issues and workforce participation issues are interconnected for carers. The TOCC (2007) found that 1 in 4 employees with caring responsibilities are likely to leave the workforce because the cost of care is too high, while 60% of unemployed carers would willingly re-enter the workforce if care was made more affordable. The issue of superannuation for carers was frequently discussed in the literature. Dow and colleagues (Dow et al. 2004) highlighted that, as retirement income is based on the number of years spent employed, caregiving can have a long-term impact on caregivers' financial wellbeing.

Many carers who are of workforce age report great difficulties with balancing their workforce participation with their caring role (Carers Australia 2004). Analysis of the Managing Caring Responsibilities and Paid Employment Survey NSW, conducted by the ABS in 2000 (Gray and Hughes 2005), found that there were higher levels of unmet need among both men and women for work arrangements to care for elderly or disabled adults than to care for children. The survey also found that both men and women with elder care responsibilities were less likely than those with child care only responsibilities to apply for greater use of flexible work arrangements due to a perception that their employer would refuse. Gray & Hughes (2005) noted that there is very little empirical information on family-friendly work arrangements for those who care for elderly or disabled adults.

Financial and workforce participation issues are likely contributors to caregivers' feelings of stress and burden. Barrett's study of 76 carers (Barrett 2005) found that the majority reported feeling tired or exhausted, frustrated, sad and worried. They also experienced a range of care-related health problems, the most common being chronic fatigue, back pain and stress. Analysis of the 2003 SDAC (Hales 2007) revealed that 29% of primary carers attributed frequent worry and feelings of depression to being a carer. Dow and colleagues' (Dow et al. 2004) review of the carer literature found that, in the majority of studies, increased care burden or strain was associated with care recipient factors, rather than carer or care situation factors.

Despite carers identifying feelings of burden, analysis of the 2003 SDAC (Hales 2007) found that 69% of spouse primary carers were not receiving assistance and claimed that they did not require it. Bittman and colleagues (2004) noted that services are most likely to be used when there is a high level of need or when need reaches a crisis point.

Cardona and colleagues' study of 42 carers (Cardona et al. 2006) found that many carers did not feel that services met their initial expectations. The carers found services to be framed in a hierarchy of needs, with access to services favouring carers who are able to strongly articulate

their needs. Furthermore, carers had the view that different government agencies can have different expectations as to what a carer should be doing. A common feeling expressed by carers in the literature was guilt for wanting to have a break from caring and feeling that others might need the limited services more than them (Cardona et al. 2006, Dow et al. 2004). Carer satisfaction with present service was also found to coexist with concerns about provision in the future, especially in the case of a carer's own illness or death.

Many researchers (Adler et al. 1995) regularly identify respite as the most urgent need. The utilisation patterns of respite care, however, at times appear to belie this. Studies have identified that among caregivers for whom respite was known to be available and provided free or at low cost, as many as 30–50% of families failed to use the service (Kosloski & Montgomery 1995).

A key gap in the scanned literature concerns the issues and experiences of carers with backgrounds and circumstances different to the 'mainstream', for example, Indigenous carers, carers from countries whose main language is not English and carers from rural and remote regions. The research that does exist flags issues for equity of service provision. For example, an Australian study of 34 culturally and linguistically diverse (CALD) carers found that a level of 'cultural competence' was required by CALD carers to understand the value of defining oneself as a carer in order to access services and payments (Cardona et al. 2006). Language issues were identified as the main barriers to articulating needs and accessing services. Additionally, CALD carers with limited English often relied on friends and relatives to inform them of services which often resulted in inaccurate information.

Cardona and colleagues also found however, that the CALD carers in their study held a number of negative attitudes towards the use of formal care (Cardona et al. 2006). Some CALD carers equated wanting to be a good citizen with not asking for too much from government services or not wanting to burden the system. On the other hand, some CALD carers were wary of approaching services and disclosing need due to a perception that formal services kept carers under surveillance. Many CALD elders were also apprehensive about using formal care due to a perception that it could lead to early institutionalisation.

A study of 76 rural and remote Western Australian carers found that the key issue for rural and remote carers was not so much the absence of services, but rather access to services (Barrett 2005). Travel time and distance, financial constraints and the physical management of the care recipient were identified as the main obstacles to accessing services.

## **2.2 Stakeholder consultations**

Consultations were undertaken with government and non-government stakeholders to discuss policy and research issues of concern to them, and to identify potential data sources for inclusion in a data repository. This section includes comments received relating to policy and research issues, while data issues and comments are detailed in section 3.2.2. The following organisations were invited to participate in discussions, and details of the discussions are included in Table 2.1:

- Carers Australia
- Alzheimer's Australia
- Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA)
- Centrelink
- Australian Bureau of Statistics (ABS)

- Department of Veterans' Affairs (DVA)
- Department of Health and Ageing (DoHA).

Issues prominent in the literature review were also raised in consultations with stakeholders. Financial support and employment issues for carers were commonly raised, as was a need for a fuller understanding of respite care use. Issues such as social isolation among carers and the burden of the role were also viewed as important, and connected to the use of respite care and ability to be involved in the workforce.

Carer groups with experiences outside the mainstream were also of interest, and little research is currently available. For example, many surveys containing information about carers do not include an Indigenous identifier. Consequently, little is known about the caring role among Indigenous Australians. Further research is also needed regarding carers from CALD groups.

Stakeholders raised concerns that current data collections do not include in-depth information for carers who are not classified as primary carers. A consequence is that little information is available about carers providing intermittent care or care for recipients with mental health conditions. Furthermore, identification of those undertaking a caring role was viewed as problematic, and often reliant on self-identification with the term 'carer'.

**Table 2.1: Issues of interest to stakeholders**

<p><b>Carers Australia</b></p> <p><b>Issues of interest identified through literature scan</b></p> <ul style="list-style-type: none"> <li>○ Confirmed those identified in literature scan remain of interest</li> </ul> <p><b>Gaps in data/research</b></p> <ul style="list-style-type: none"> <li>○ Carers of people with mental illness — an area of interest, for which little data is available. These carers have very different needs than carers of people with physical disability.</li> <li>○ Marginalised groups — carer information is needed for: multicultural, young, ageing and Indigenous carers.</li> <li>○ Respite usage information is needed to assess the impact of respite on quality of life. A relationship between health &amp; quality of life exists for both carer and care recipient.</li> </ul> <p><b>Limitations of current data</b></p> <ul style="list-style-type: none"> <li>○ A focus on 'primary' carers in most collections rather than family wide caring roles means that some carers are missed.</li> <li>○ Palliative care may be for less than six months, and these are therefore not classified as primary carers. Palliative carers are not eligible for Carer Payment/ Allowance</li> <li>○ Issue of who identifies with the term 'carer'. Many carers are missed because they do not identify themselves as such.</li> </ul>
<p><b>Carers Australia state and territory CEOs</b></p> <p><b>Gaps in data/research</b></p> <ul style="list-style-type: none"> <li>○ Carers of people with mental illness</li> <li>○ How are carers using education and training programs?</li> <li>○ What are the rates of transitions between the Carer Payment/Carer Allowance and the Age Pension?</li> </ul>
<p><b>Australian Bureau of Statistics (Subject Matter Area)</b></p> <p><b>Issues of interest</b></p> <ul style="list-style-type: none"> <li>○ Recent concerns about the need for superannuation for carers and how this applies to government and industry schemes which are based on number of years in employment. There is no restriction on carers creating and funding a private super scheme, but it can be hard to do this on a limited income.</li> </ul>

*(continued)*

**Table 2.1 (continued): Issues of interest to stakeholders**

**Department of Families, Housing, Community Services and Indigenous Affairs**

**Issues of interest (many of these represent gaps in current research)**

- Social participation by carers
- Health and wellbeing (particularly depression)
- Duration of care and the caring role
- Employed carers (education, occupation, workplace policy)
- Staying in the home/providing care at home
- Carers caring for multiple recipients
- Preference for formal and informal care
- How many carers are in the role because they want to versus because they have to?
- CALD carers
- Older carers (caring for a partner or disabled child by a person who is ageing themselves)
- Care transitions
- Respite care (types, definitions, unmet need)
- Effect on family of being a carer
- Education & training for carers

**Limitations of current data**

- Shared caring role (current focus on 'primary carer' is too limited)

**Alzheimer's Australia**

**Issues of interest**

- There are strong relationships between carer burden and type of disability, functional limitations and role of carer (primary or other).
- Burden of care in families
- There are particular issues for carers of people with dementia.
- Social engagement—including programs that can support engagement in the long term
- Need for 'elastic' care
- Non-use of available care
- Focus on carers' needs in addition to recipients' needs (carers need: flexibility, interaction, ongoing support. Often a reluctance to engage, leading to depression & isolation. Can have cultural link.)

**Gaps in data/research**

- Issues such as multiple carers and reluctance to access support need further investigation.

**Limitations in data**

- Carer identification—quantifying carers.

**Department of Health and Ageing**

**Issues of interest**

- Interest lies in service use and non-use, and cross-program duplication of services.

Some of the data gaps and current problems which exist for investigating these issues could be resolved or diminished by improved data collection activity. For example, variables relating to carer burden and stress are included in the SDAC. However to date the sample size of this survey has limited its analysis at different geographic levels or for different types of carers (for example, carers of people with mental illness compared with carers of people with intellectual disability).

Increasing the sample size of the survey would go some way to filling some gaps in data but there will always be limits to this.

Similarly, data development work designed to improve consistency of definitions between collections and/or to improve the identification of different types of carers would also reduce some of the gaps and problems identified by stakeholders. For example, there could be a coordinated effort to introduce Statistical Linkage Key (SLK) capability for carer details where this does not already exist – to illustrate, CSTDA has carer information, but records can only be linked to other data sets using the care recipient SLK because carer SLK is not collected.

Nevertheless, there are a number of issues where the use of multiple data sources has the potential to enrich the kind of information available for decision makers, planners and advocates. Table 2.2 provides examples of these where existing data are available. Multiple data sets can be used to compare characteristics of an overall population of carers with those of program clients; to assess the extent to which people in potential target populations access support services; and to fill gaps in information available from each data source.

A CNDR is not strictly necessary in order to use multiple data sets, but would facilitate the knowledgeable analysis of relevant data sets in order to explore an issue of interest and improve the efficiency of compiling and analysing data. However, linking data from multiple data sets requires the existence of some kind of repository even if the repository has a life span limited to a particular project and/or data access sharing protocols.

**Table 2.2: Potential of CNDR to address selected stakeholder issues**

Broad issue	Potential for research using a CNDR
Carer identification	Bringing together a variety of sources would highlight differences in carer identification and facilitate data development activity to improve this.
Respite use	SDAC provides population level data about use of different types of respite care, but does not identify through which programs such support is accessed. Program data (e.g. NRCP, HACC) provide information about users of respite care, duration and frequency of support and information about the care recipient. Using all these data sources together can enrich the information available.  Linking data about respite care facilitates analysis of patterns of respite use
Special groups	Small population groups can be examined effectively using census data. Indigenous and CALD identification is available in some administrative collections. CALD status is available in most surveys, while Indigenous status is excluded in most cases due to small numbers in the sample. These data can be used to derive estimates of the size of the carer population in these subgroups. Combined with program use data, issues such as access to and use of carer support and payment programs can be investigated.
Carer burden	Variables relating to burden are available in SDAC and certain carer subgroups can be compared with each other. Comparison with program data to investigate access to and user of carer support services
Financial issues	Included in SDAC and Carer Payment/Carer Allowance data. Survey of Employment Arrangements, Retirement and Superannuation (SEARS) allows investigation of superannuation accessed by some carers.
Employment	Data available in NRCP and ABS collections.
Care transitions	Data linkage within a repository would allow study of patterns of service use across programs.
Education and training	Little data is currently available to investigate the training and education undertaken by carers to strengthen capacity in the caring role.

# 3 Scope and feasibility of possible CNDR

## 3.1 Sources of carer data

A variety of data sources have been examined in this report for potential inclusion in a data repository, although other collections exist that also include information relating to carers. Data sets included in this report are limited to large-scale or repeating data sets. The data examined includes:

- administrative data (Home and Community Care (HACC), Commonwealth State/Territory Disability Agreement (CSTDA), Aged Care Assessment Program (ACAP), National Respite for Carers Program (NRCP), Carer Payment/Carer Allowance (CP/CA), Community Aged Care Packages (CACP), Extended Aged Care at Home/Extended Aged Care at Home – Dementia (EACH/EACH-D) and Veterans' Home Care (VHC)
- census data (CACP census, EACH census, Community Care Census (CCC) and ABS Census of Population and Housing)
- survey data (Survey of Disability Ageing and Carers (SDAC), General Social Survey (GSS), Household Expenditure Survey/Survey of Income & Housing (HES/SIH), Multi-Purpose Household Survey (MPHS), National Health Survey (NHS), Survey of Employment Arrangements, Retirement and Superannuation (SEARS) and Time Use Survey (TUS).

Full details of these collections are included in tables 3.1 to 3.3.

A variety of collection purposes and methods are found in these data sources. Data custodians and time periods vary, as do data quality improvement and access protocols. For collections such as ABS surveys and HACC, clear data access protocols are in place. However, for programs such as ACAP and NRCP these have not been established.

Definitions including the definition of a carer and the reference person for the collection also vary. In some collections, data is collected for the care recipient and includes information about their carer, while in others information is collected for the carer. In the case of Veterans' Home Care, data is collected for the veteran who may be either a carer or a care recipient. Appendix 1 contains a broad mapping of carer and care recipient data items across these collections.

## 3.2 Data issues

There are two broad types of data issues associated with establishing a CNDR. First, there are issues concerning the data sets themselves. These include data quality issues, and consistency between collections. Secondly, there are issues pertinent to the inclusion of data sets within a repository. Such issues include the physical format of data, and data use and access restrictions.

## Data quality and consistency

Consistency across collections varies depending on which variables are examined (tables 3.1, 3.2 and 3.3). For example, carer co-residency is available and similar across most collections, and could be derived for most ABS surveys. Conversely, consistency in carer identification is a significant issue. In the collections examined, definitions of a carer varied. To illustrate, CACP Census data establishes the presence of a carer by asking a care recipient to answer the question ‘do you have a person such as a family member, friend or neighbour that provides regular and sustained care and assistance without payment other than a pension or benefit?’ Similarly, other administrative data sets such as HACC use a broad definition of a carer that can include those providing occasional assistance. By contrast, a carer must provide, or be likely to provide, ongoing care for six months or more to meet the SDAC definition.

**Table 3.1: Administrative data collections included in the scoping study**

Full name of collection	Abbreviation	National data custodian	Reference person	Time period(s)	Linkage key available/able to be generated
Home and Community Care	HACC	HACC officials (managed by DoHA)	Version 1: separate records for carer and recipient Version 2: Joint record	Collected quarterly Annual financial year data set V1 2001–02 to 2004–05 V2 from 2005–06	Carer and care recipient
Commonwealth State/Territory Disability Agreement	CSTDA	AIHW	Recipient	Annual since 2003–04	Recipient
Aged Care Assessment Program	ACAP	DoHA (access considered on an ad hoc basis)	Recipient	Collected quarterly Annual financial year data set V2 from 2003–04	Recipient
National Respite for Carers Program	NRCP	DoHA (currently no access protocols due to data quality concerns)	Carer	Undetermined	Carer
Carer Payment/Carer Allowance	CP/CA	Centrelink/ FaHCSIA	Carer	Ongoing	Not available
Community Aged Care Packages	CACP	DoHA	Recipient	Ongoing	Recipient
Extended Aged Care at Home/Dementia	EACH/ EACH–D	DoHA	Recipient	Ongoing	Recipient

**Table 3.2: Census data collections included in the scoping study**

Full name of collection	Abbreviation	National data custodian	Reference person	Time period(s)	Linkage key available/able to be generated
ABS Census of Population and Housing	Census	Australian Bureau of Statistics (ABS)	Carer	2006	Not available
CACP Census	CACP Census	AIHW/DoHA	Recipient	2002	Recipient
EACH Census	EACH Census	AIHW/DoHA	Recipient	2002	Recipient
Community Care Census (CACP, EACH, EACH-D, NRCP direct respite)	CCC	DoHA (access considered on an ad hoc basis)	Recipient	2008	Recipient

**Table 3.3: Population survey data collections included in the scoping study**

Full name of collection	Abbreviation	National data custodian	Reference person	Time period(s)	Linkage key available/able to be generated
Survey of Disability, Ageing and Carers	SDAC	ABS	Carer and recipient	1993 1998 2003	Not available
General Social Survey	GSS	ABS	Carer	2002 2006	Not available
Household Expenditure Survey/Survey of Income and Housing	HES/SIH	ABS	Carer receiving Carers Payment or Carers Allowance	Annually 1994–95 to 2002–2003 Biennially from 2002–03	Not available
Multi-Purpose Household Survey	MPHS	ABS	Carer receiving Carers Payment or Carers Allowance	Annually from 2004–05	Not available
National Health Survey	NHS	ABS	Carer receiving Carers Payment or Carers Allowance	1989–90 1995 2001 2004–05	Not available
Survey of Employment Arrangements, Retirement and Superannuation	SEARS	ABS	Carer	2000 2006	Not available
Time Use Survey	TUS	ABS	Carer	1997 2006	Not available

In general, ABS survey data do not include information about the care recipient and have a very specific focus (the exception is the ABS SDAC). The ABS recommends SDAC as the most accurate source from which to gain estimates of carer numbers (ABS 2006). However, other ABS collections also identify carers to some extent and could be used to gain understanding of specific issues in greater depth. For example, the National Health Survey and Survey of Income and Housing both allow identification of carers receiving Carer Payment and Carer Allowance, and could be used to examine health and income issues in depth.

Carer Payment and Carer Allowance data are collected for the purpose of administering payments rather than for research purposes. Consequently, there are a number of data quality issues, particularly surrounding 'receipt of other payments' data and little reporting is available from these data sets. The data available are published at a broad level in Centrelink Annual Reports, with no information collected about the care recipient. Similarly, data linkage work across DoHA administrative data sets was recently undertaken by the Allen Consulting Group, with a summary available on the DoHA website (DoHA 2007). In relation to carer data, significant data quality issues were apparent in comparison to other data areas. These were shown to impact on both carer issues and service use data. For carer data, there was difficulty matching between collections, as well as internal quality issues affecting carer data.

Respite care was identified by stakeholders as an area where data are particularly fragmented. Data are held by FaHCSIA, DoHA and by the states, but an overview is not currently available. Respite care data are explored further in Section 5.

## **Repository issues**

In bringing together a variety of data sources in a repository, there would be significant technical issues. For administrative data sets, documentation including business rules and coding is often scarce and file formats can be complex and unique to the custodian organisation. Carer Payment data are an example of such a data set. The current data format is complex, and requires expert knowledge to extract data. A new database has been developed within FaHCSIA for Carer Allowance data, and a similar database is currently under development for Carer Payment data.

Data custodians also have a variety of access protocols in place, which can include ethics committee clearance and other access procedures which could impact on inclusion of particular collections in a data repository. Again, Carer Payment is a good example of the complexity involved. While the data set is owned by Centrelink, access protocols are determined by FaHCSIA in relation to this data.

Controlling access to and use of data sets is a common mechanism for managing data security and compliance with privacy and other relevant legislation. It also assists with the management of problems related to complex data with limited documentation and concerns about quality. Pre-conditions for establishing a repository of carer data would include the development of appropriate, agreed arrangements to manage these concerns; to comply with legislated requirements to protect the privacy and confidentiality of potentially identifiable data; and to ensure that data owners/custodians are kept informed about data use and especially publication.

# 4 Possible models for a CNDR

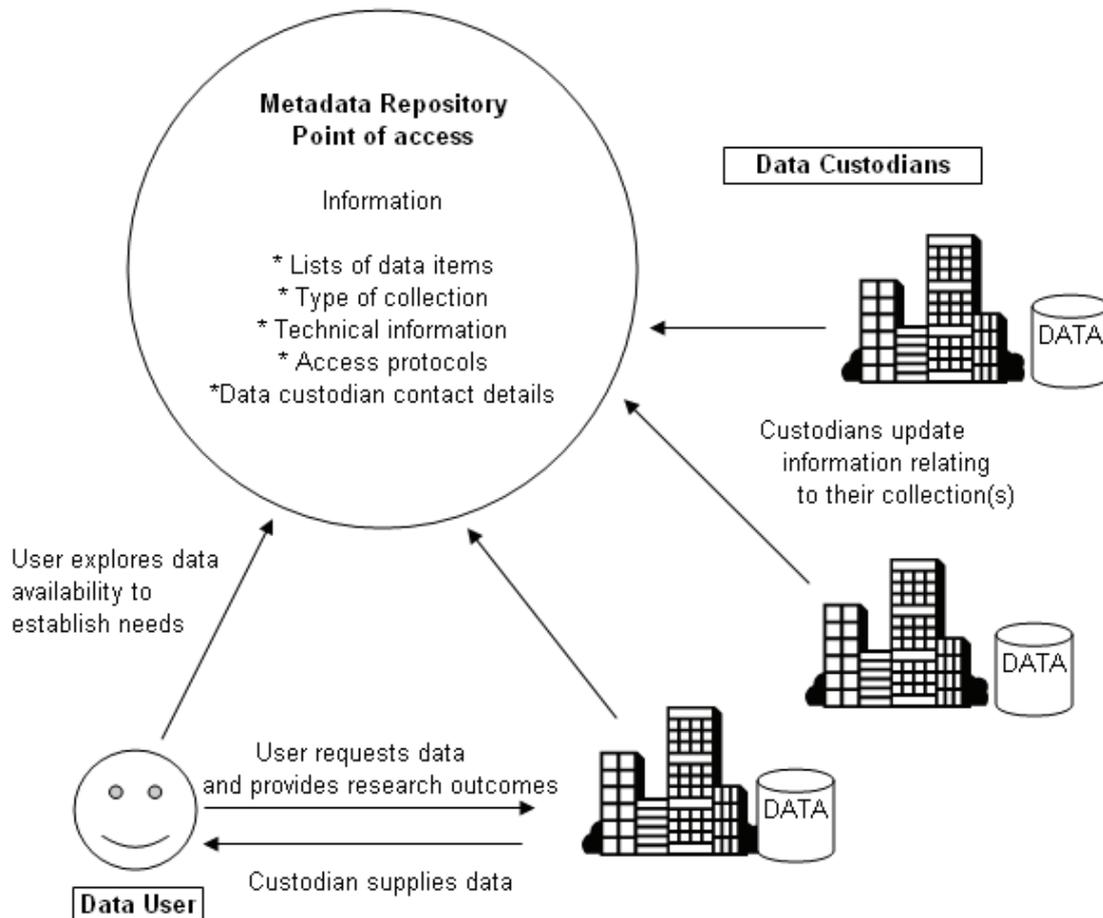
Support in principle for the concept of a carer data repository was received from the majority of stakeholders, and was strongest from advocacy groups. There was recognition of a need for wider data access and research relating to carers, but concerns from data custodians regarding privacy and data access. Stakeholders recognised the value of a CNDR in improving access to data and visibility of carer research, and in reducing duplication of research. It was felt by some stakeholders that a CNDR would enable administrative collections currently not widely reported to provide maximum research benefit for the clients included in the collections.

Data custodians were concerned over the uses of confidential data collections. They felt they had a duty of care with regard to the confidentiality of their data holdings, and that a CNDR may result in a loss of knowledge of research undertaken, and a loss of ability to assess the appropriateness of data requests.

A Carers National Data Repository could take one of a number of forms, with varying degrees of establishment and maintenance resources required. Three repository and data governance models were proposed by and discussed with stakeholders during the consultation process. In broad terms, these can be described as a repository of metadata only without access to data; a virtual 'hub' from which access can be gained to data held by data custodians; and a physical data repository, with data collections or copies centrally located. These models can be viewed as separate possible final outcomes, or as 'levels' or 'stages' in the development of a full Carers National Data Repository.

## 4.1 Metadata repository/data portal/data directory

A 'metadata only' model represents the simplest proposed form of a Carers National Data Repository. It is also the least controversial model and would command general support from all stakeholders, however this does not mean it is without risk or cost. A repository such as this would not include any data, but would provide a central point from which to gain information about what is available and from whom. The repository would include descriptions of available data collections, including data items, collection methodology, data dictionaries, contact details and access protocols.



**Figure 4.1: Model 1 – Metadata repository model**

Currently, such information is scattered and frequently incomplete or difficult to obtain. Many data sets that identify carers have difficulty in maintaining currency of metadata. The development of a repository would facilitate evaluation of available metadata for quality and consistency across collections. Extensive liaison would be required with data custodians to locate existing information and to gather undocumented details. The information would then need to be presented in a consistent format that is easily understood and accessed by clients. Beyond establishment, this model would require a regular maintenance cost to review and update metadata and ensure currency of information.

A logical location for a carers' metadata repository would be within the Metadata Online Repository (METeOR). METeOR is Australia's repository for national metadata standards for the health, community services and housing assistance sectors. The system was developed by the AIHW, and provides free online access to a wide range of nationally endorsed data definitions.

The main risks associated with this model relate to control and coordination of data use. In the absence of a national policy framework and guidelines for the secondary use of administrative data, access control would remain distributed and inconsistent, and control of data use would be variable. If data custodians are unwilling to grant information requests, data usage would be limited. If the decisions and outcomes of data access requests are not made publicly available, there is a high potential for duplication of data requests and subsequent research, as each request is fully independent. If not located, configured and supported correctly, a metadata only repository also carries the risk of atrophy over time. Without some kind of webpage access count,

it would be difficult to determine the extent to which the repository is being used. Without visibility of use, the value of such a repository is likely to become less clear and arguments in favour of its resourcing become difficult to sustain. A high level of engagement is required from data custodians to respond to queries, maintain up-to-date metadata, and a commitment of some degree of in-kind resources. There are considerable inefficiencies for the data user in obtaining, validating and analysing data as a result of liaising with multiple data providers. There is also limited capacity to develop expertise in analysing the relevant data sources. This model would highlight issues associated with data definitions and consistency, but there would be no locus of responsibility for driving data improvement.

## 4.2 Decentralised virtual hub

A virtual repository builds on the first model, as it would first require the development of a ‘data directory’. The key improvements over a metadata repository are in data access and use. It allows data usage procedures to be streamlined and consistent. As with the first model, a virtual repository would facilitate the development of improved and readily accessible technical documentation.

Under this model, data custodians would physically retain their data and provide access to users via a secure central web-based access point. User access to data would be streamlined with advantages to users and the potential to respond more efficiently to duplicate user requests. There is scope to allow different levels of access to different users, controlled and monitored by the data custodian. For example, metadata and published data may be freely available to all users. Confidentialised unit record files from ABS surveys or broad-level aged care program data could be available to approved users, while a higher level access to full data sets may be available to users within data custodians’ own organisations.

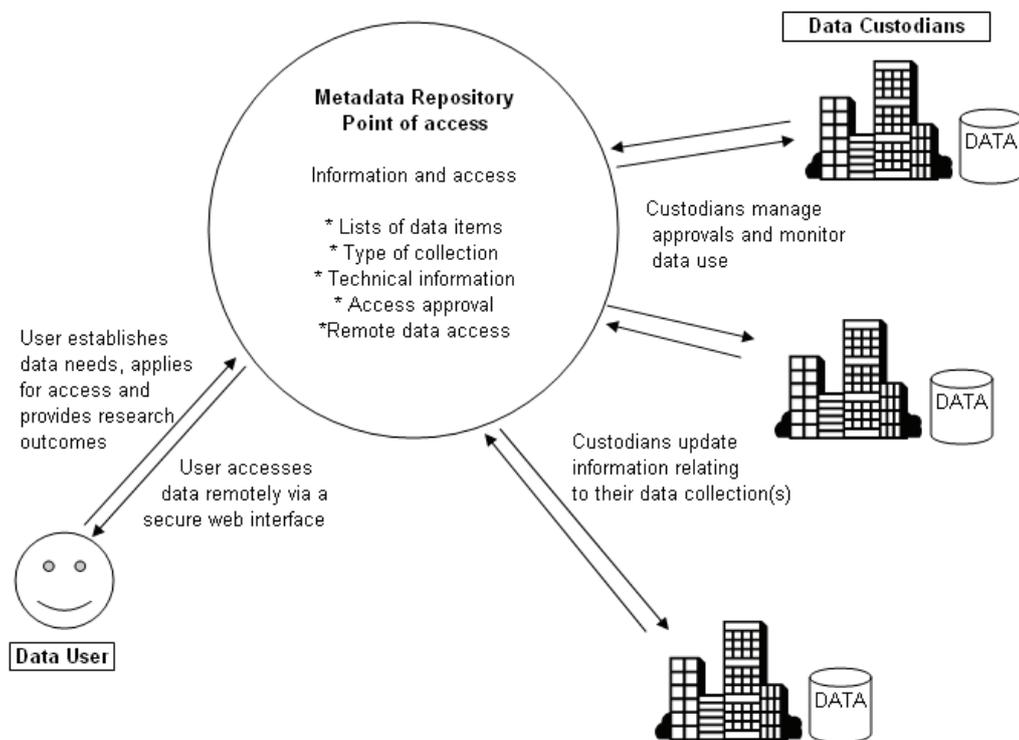


Figure 4.2: Model 2 – Decentralised virtual model

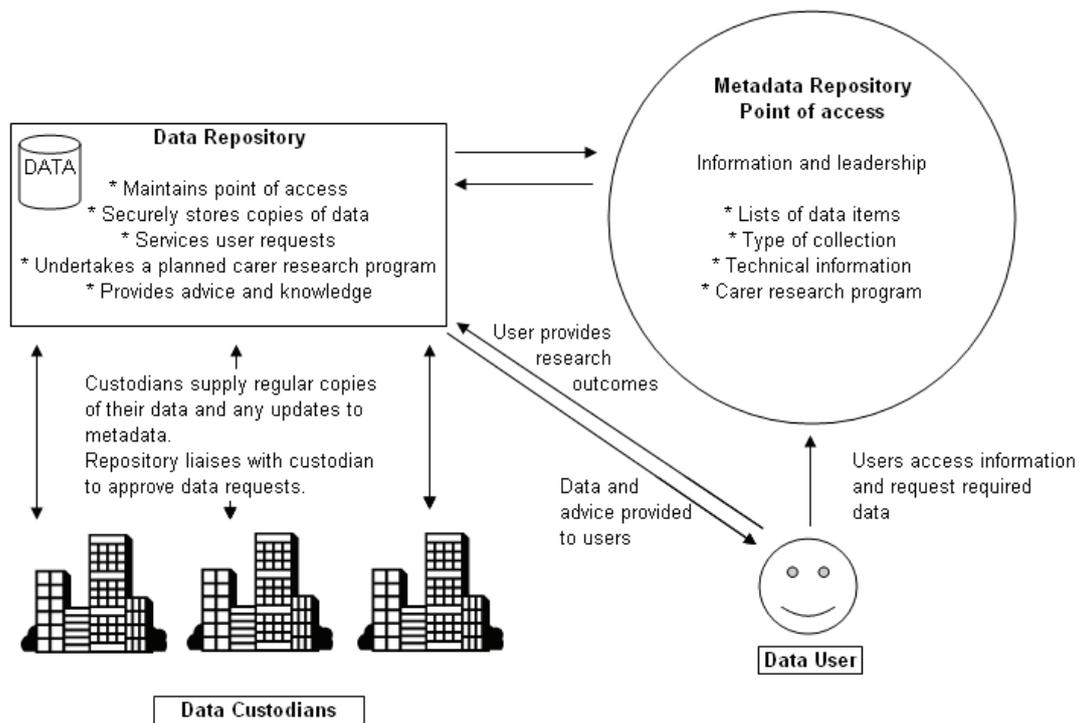
This model would require a considerable investment in resources to both develop clear and consistent metadata and to develop secure web linkages and data access protocols. It is envisaged that after initial set-up, data custodians would be required to manage repository access and to keep data and metadata current. As the data is not physically located in a single repository, it is not feasible for ongoing maintenance to be the responsibility of a dedicated repository staff. As with Model 1, a high level of engagement is required from data custodians for this model to be successful. Similarly, there is no capacity in this model to fully support a high quality analytic program of work across the range of data sets.

The issue of analysis involving linked databases would require further consideration under this model where data remains physically separated. This model could assume that the researcher undertook data linkage once they had received all relevant data sets, subject to obtaining approval from data owners and ethics committees. The repository could facilitate obtaining these permissions. The repository might also provide technical support and assistance with data linkage. This approach has high risks in terms of data security and privacy. Not all users or user organisations would possess the kind of secure environment within which data linkage can be done responsibly nor have the technical capacity to undertake data linkage. The potential for considerable variation in linkage methodologies may be detrimental to the goal of building a coherent and consistent evidence base.

A different option could see an extension of the model to incorporate a physical repository for data linkage purposes. Data linkage would be undertaken within the repository and de-identified, confidential linked data supplied to the user. This model is akin to that used by some state-based data linkage centres (for example, the Centre for Health Record Linkage in NSW) and by the AIHW in respect of linkage to the National Death Index.

### **4.3 Centralised physical repository**

The third model discussed is a centralised physical data repository. Under this model, data custodians would supply metadata and regular copies of their data to the repository organisation. The repository would maintain an online point of access, similar to the metadata repository described in Model 1. However in this case, the repository staff would manage and respond to requests from data users in consultation with data custodians. This model is less resource intensive for data custodians, but would require a substantial investment of staff time for the repository organisation.



**Figure 4.3: Model 3 – Centralised physical model**

A key advantage of having the data in one physical location is the potential for value-added projects, such as linkage work, and the ability to undertake a coordinated program of expert independent research, reported on a regular basis. It would enable the repository organisation to develop an expert knowledge base in carer research and to build the capacity of data users to undertake effective research. A central point of access to a number of collections containing carer data also allows research to be monitored easily, so that carer research in general would be less ad hoc. While users are likely to want to be able to access linked data sets, issues of privacy are considerable. Consequently, linkage work would most likely be undertaken by the repository. However, de-identified linked data could be provided to researchers subject to appropriate approval procedures.

A further advantage is that a physical repository would retain historical data, which is often lost from administrative data collections. Previous copies of both data and metadata would be retained by the repository, permitting time series analyses as the repository grows.

The expense of maintaining a physical data repository is an obvious disadvantage of this model. In addition, there are many technical issues in providing copies of data from different systems in a form that can be centrally maintained by the repository. During stakeholder consultations, data custodians expressed concern regarding provision of data to the repository. These concerns derive in part from anxiety about the use of complex data of variable quality and partly from a desire to retain control of data access arrangements. It would be vital to establish a high degree of trust between custodians and the data repository for this model to be successful and for clear agreed arrangements in relation to data access to be established. Regular reporting on both research undertaken by the repository and on data supplied to users would be required to allay custodian's concerns surrounding privacy and data access.

# 5 Case study: exploring the use of respite care using multiple data sets

This section examines how multiple data collections can be used to explore the use of respite care programs. It includes a brief discussion of what can be done with these data sets, and the limitations of analysis across them. There are fundamental differences between these data sets including:

- the definition of a carer
- reporting of assistance types provided
- whether information is collected about the carer or the care recipient and which of these two is the reference person for the data set
- the scope and completeness of the data items collected.

A number of government programs provide a variety of forms of respite care. Respite care can include residential respite care, in-home respite care of short (a few hours) or longer duration (a few days), host-family respite, flexible and/or vacation respite care, and centre-based day care. The stated purpose of most forms of respite care provided in the community by aged care programs is to give the carer a break from caring duties. However, the purpose of centre-based day care is to assist the individual care recipient to develop, maintain or support the capacity for independent living and social interaction, and it is provided to groups. Centre-based day care is generally out of scope for this analysis which is concerned with the use of respite care as a support service for carers. An exception is where SDAC data is used, as the SDAC definition of respite care includes centre-based day care. Host-family respite care is provided through at least one program but is not recorded separately from respite provided in the recipient's own home.

This analysis examines data from SDAC and from a number of key aged care data collections (HACC Minimum Data Set (MDS), NRCP MDS, ACAP MDS and some ad hoc census collections, such as the 2002 census of CACP program and the 2002 census of EACH packages). Each of these collections has information on provision of respite care, but the main person about whom information is collected (the reference person) differs between collections.

These administrative databases are generally large and complete in relation to information about the provision of service but collect the minimum of data items consistent with policy and service delivery goals and objectives. Few collect information about issues such as the carer's need for support or duration of caring role. And none contain information about people who do not use their services. Use of administrative databases also raises issues around consent and privacy, as the primary purpose of such collections is not data analysis for research purposes.

In contrast, SDAC is a population survey with a wide range of questions about both people who do and do not receive assistance, their characteristics, the receipt of services, unmet need, and the reasons for not receiving services. However, the capacity to drill down to investigate associations between items can be restricted by the sample size. Specifically, SDAC contains information about respite care provision to primary carers, including residential respite care, and is the only data examined which contains information about reasons for not using respite care. However, it does not contain information about the use of respite care by carers who do not fit the ABS definition of a primary carer, nor does it contain information about the use of residential respite care for recipients without a carer.

The definition of a carer may differ between these data collections. Generally data are collected on carers who 'provide regular and sustained care or assistance to another person, without receiving payment other than a pension or benefit' (AIHW 2004a). However, the ACAP MDS includes carers who are private employees (but not those organised by formal services). SDAC includes subcategories of carers, with primary carers needing to provide sustained care (at least 6 months) to a person with a core activity limitation.

Each of these data collections has a slightly different view of the provision of respite care. In some collections, the recorded recipient of the respite care is the carer (HACC, NRCP, and SDAC) and in others, the care recipient (ACAP, CACP and EACH census). Different data sets also cover different aspects of the population according to the target group the program helps.

Information on the provision and use of residential respite care is recorded in the Aged and Community Care Management Information System (ACCMIS), but this data does not include carer details. Nor is information collected about the existence of carers for people who are permanent residents of residential aged care, although in some cases the amount of assistance provided to a resident may be substantial. Previous analysis by the AIHW discusses the role of residential respite care in supporting people in community care and/or as a stepping stone to permanent residential care (AIHW: Karmel 2006).

However, ACCMIS data can only be used to explore the role of residential respite care in supporting carer needs if it is linked to ACAP MDS data (which includes some carer data). An analysis of this linked data is currently being undertaken by the AIHW as part of an investigation into the take-up of residential respite care. Some preliminary broad findings from this analysis are reported here, illustrating the potential for enriching analysis by bringing data sets together in this way. By this means information available from some data sets can be used to inform us about factors influencing the use and provision of different aged care services.

## **5.1 How many carers use respite care services?**

An apparently simple question of interest to policy makers and service planners is to know how many carers use respite care services. SDAC is the most appropriate source of data for answering this question. In SDAC, information is collected for people with a disability, older people (over 60 years) and their carers, including information on respite care use by primary carers aged 15 years or older. Primary carers are identified by care recipients as those people who provide the most informal assistance for one or more of the core activities (communication, mobility and self-care), which is or will be ongoing for at least 6 months. Primary carers over 15 years of age are then usually personally interviewed. In the 2003 survey a number of identified carers were not interviewed (unconfirmed primary carers). Information on the use of respite care is not collected for this latter group nor for primary carers under 15 years.

Findings from the survey indicate that in 2003, residential respite care was only used by 2.3% of primary carers in the previous 3 months. An additional 11% had either used some other form of respite care in the past 3 months (including centre-based day care) or had used some form of respite care in the past. Of all primary carers, 87% had never used respite care of any sort. Female primary carers were more likely to have used some form of respite care (15%) than males (9%). Women (2.5%) were also slightly more likely to use residential respite than men (1.9%) and to use more than one form of respite care (Table 5.1).

**Table 5.1: Use of residential respite care in the last 3 months, by co-resident primary carers of recipients with a severe or profound core activity limitation**

Sex of carer	Whether primary carer used residential respite care in the last 3 months					Total
	Used residential respite in the last three months	Has used respite care in the last three months but not residential respite	Has used respite care but not in the last three months	Total having used any type of respite care	Has never used respite care	
	<b>Number</b>					
Male	2,100*	5,000*	3,400*	10,500	100,300	110,800
Female	6,200*	14,100	18,000	38,400	211,300	249,600
<b>Persons</b>	<b>8,300*</b>	<b>19,100</b>	<b>21,400</b>	<b>48,800</b>	<b>311,600</b>	<b>360,500</b>
	<b>Per cent</b>					
Male	1.9*	4.5*	3.1	9.4	90.6	100.0
Female	2.5*	5.7	7.2	15.4	84.6	100.0
<b>Persons</b>	<b>2.3*</b>	<b>5.3</b>	<b>5.9</b>	<b>13.5</b>	<b>86.5</b>	<b>100.0</b>

*Note:* Numbers have been rounded to the nearest 100 while percentages are calculated using the original estimates.

\* Figures have a relative standard error (RSE) of 25% or greater.

*Source:* AIHW analysis of ABS SDAC 2003

While the survey suggests very small numbers of primary carers had used respite care, this is an underestimate of respite care use. For example, SDAC only collects residential respite and centre-based day care as a respite service provided to carers (and specifically to primary carers living in surveyed households). However, in reality, these services can be accessed by a care recipient without a carer. Based on the AIHW preliminary analysis of the linked data in the PIAC cohort<sup>3</sup>, around 14%–15% of residential respite is provided to a care recipient who does not have a carer and is therefore out of scope for SDAC.

It is likely that a larger proportion of centre-based day care as a recognised service type would also be out of scope as HACC (the principal provider of centre-based day care) has a lower proportion of care recipients with a carer than most other aged care services. However, centre-based day care services provided to a care recipient should be picked up by the SDAC community participation item 'Frequency of attendance at supervised activity programs'. When considering the results of analysis of respite care provision for primary carers, it should be noted that centre-based day care is included in categories where the type of respite care is not specified.

Sample size precludes more detailed analysis of assistance for primary carers as this involves only 687 records, representing around 360,455 people (110,808 males and 249,646 females). For primary carers using residential respite care this is reduced to 15 records making it difficult to produce reliable information on factors influencing the use of and need for this service. Analysis of issues relating to people who have never used respite care services involves a larger number of records (591) and is likely to be more reliable.

While most of the administrative data are concerned with the provision of respite care services, the ACAP MDS collects information about prior use of respite care by people receiving an

3. Pathways in Aged Care (PIAC) is an AIHW data linkage project using aged care program data. See Section 5.3.1 for a more detailed description.

assessment for aged care services. It is therefore useful to compare SDAC and ACAP data in relation to respite care use.

Comparison of SDAC figures on the use of respite care with administrative data is complicated by the different time periods used, as it is not possible to multiply service use in a 3-month period to derive service use over the 12-month period used for administrative data collections. Comparable figures can only be derived where service use data can be broken down by quarter or the data collection allows date restrictions on the analysis of service use. This has not been attempted in this study, which is limited to a broad comparison of the patterns of respite care use evident in both data sets. In addition, SDAC includes a larger percentage of younger people with disability than the ACAP MDS because all younger people with disability are in scope for SDAC, but are unlikely to be assessed for approval to use aged care services.

## **Respite care use by ACAT clients**

The Aged Care Assessment Teams (ACATs) determine eligibility for assistance from CACPs, EACH and EACH-D packages, residential respite care and permanent residential aged care. The teams then make recommendations on the most appropriate living environment for the care recipient's long-term care needs, the government-funded programs recommended as the source of assistance for the client, and recommendations for the use of respite care. At the time of assessment by an ACAT, a client may be living in the community, in residential aged care, or in a hospital or other institution.

The ACAP MDS is a rich source of information on the services received by the care recipient at the time of assessment (including respite care) and whether this assistance is received from formal or informal sources, the health conditions and functional limitations of the care recipient, and the recommended long-term care setting. Where the recommended long-term care setting is the community, the data set also contains recommendations on the support programs to assist the recipient and their carer, including residential respite care.

Data in this collection is recorded for each assessment against the details of the care recipient with only the standard carer items (availability, co-residency and relationship to the care recipient) recorded in relation to the carer<sup>4</sup>.

There are some issues and idiosyncrasies in relation to data published in the ACAP MDS annual report:

- individuals can have more than one assessment
- data are reported for assessments rather than for individual clients, as the person's condition or situation can change, although reporting can be done for individuals
- availability of carers is reported against the total number of assessments including assessments where only a referral was recorded, not against the number of completed assessments which would minimise missing data
- the scope of carers in the ACAP MDS includes private employees, although this is only a very small proportion of carers (around 150 out of 128,000 in 2005–06).

---

4. Sex of the carer can be derived from the data on the relationship of the carer to the care recipient.

**Table 5.2: Use of respite care at the time of assessment, recommendations for the use of respite care for people living in the community, and approvals for residential respite care, ACAP assessments 2005–06**

	Used respite care at assessment <sup>(a)</sup>	Recommended for respite care <sup>(b)</sup>	Approved for residential respite <sup>(e)</sup>
No respite care used	118,286	25,897	
Residential respite care only <sup>(c)</sup>	15,046	47,646	
Non-residential respite care only <sup>(d)</sup>	6,123	2,500	
Both residential and non-residential care	2,408	12,925	
<i>Total: residential respite <sup>(c)</sup></i>	<i>17,454</i>	<i>60,571</i>	<i>94,752</i>
<i>Total: non-residential respite <sup>(d)</sup></i>	<i>8,531</i>	<i>15,425</i>	
Unable to determine	2,117	839	
Not stated	2,002	1,232	
<b>Total</b>	<b>145,982</b>	<b>91,039</b>	<b>94,752</b>

- (a) Includes only complete MDS v2 assessments of clients living in the community at assessment but excluding 'not applicable' responses.
- (b) Includes only complete MDS v2 assessments that include a recommended long-term living environment in the community, but excludes 'not applicable' responses. Recommendations for the use of respite care are not made for people whose recommended long-term living environment is residential care.
- (c) Availability of a carer does not determine access to residential respite care.
- (d) Non-residential respite care through NRCP or HACC is applicable only to care recipients with a carer, as this is considered a service for the carer.
- (e) 62,351 high-level care residential respite care approvals and 32,401 low-level residential respite care approvals.

Source: ACAP NDR (Aged Care Assessment Program National Data Repository) 2007: Tables AB18, AC22, and AC26c).

In 2005–06 there were 198,538 assessments in the ACAP MDS, including incomplete assessments where full data may not be available. Of these, 176,048 were full assessments although not all were completed (that is, have associated recommendations and approvals for service use). For 127,910 assessments the recipient had a carer (74,431 co-resident carers and 52,686 non-resident carers) at the time of assessment (ACAP NDR 2007: Tables AB11 and AB12). People undergoing an ACAP assessment are generally older than the population of people with disability reported by SDAC. While younger people with disabilities may be assessed, approval is not generally given for provision of aged care services unless no other more suitable care is available. In 2005–06 less than 3% of assessments involved people under the age of 60 years. In total, 5% of assessments were for people under 65 years (ACAP NDR 2007: Table 29).

The majority of ACAP assessments were for people who had not used respite care (81%). About 12% of assessments were for people who had used residential respite care and 6% for people who had used non-residential respite care types. In total, respite care in some form had been used by people in relation to 23,577 ACAP assessments (Table 5.2).

While absolute numbers of people using respite care differ (reflecting differences between the SDAC and ACAP MDS), both SDAC and the ACAP data report that more than 80% of their study populations have not used respite care.

## 5.2 Source of respite care services

Administrative data from government programs which provide respite care services can be used to examine use of different types of respite care and the characteristics of service users.

The main source of non-residential respite care at assessment for ACAT clients was listed as 'Carer respite' (NRCP assistance from Carer Respite/Resource Centres) – 7,158 out of 168,766 assessments where the person was receiving help from a government-funded community care program (ACAP 2007: Table AB17). This is around 84% of those who reported receipt of some form of in-home respite care at assessment (8,231 assessments). Other respite care recipients may be receiving non-residential respite care from HACC or as part of a CACP or EACH package.

For those with a recommendation for living in the community with government assistance, 15% (19,824/130,423) had a recommendation for assistance from 'Carer respite' (ACAP NDR 2007: Table AC21). This is greater than the number recommended for respite care (see Table 5.2) and so is likely to include carer support/education/advocacy services.

### National Respite for Carers Program

This program is 'designed to support and assist relatives and friends caring at home for people who are unable to care for themselves because of disability or frailty' (DoHA <<http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-carers-nrcp.htm>>).

It is a potentially rich source of data about a wide range of direct respite care, including centre-based day care (AIHW 2007a: Box 3.5). However there is little published data for this program and there does not seem to be any mechanism for access to unit record data, due in part to data quality concerns. Tables need to be requested from DoHA.

Table 5.3 shows the number of carers receiving direct respite care from NRCP in 2004–05. For the same period, *Dementia in Australia* (AIHW 2007b) published material on the number of carers assisted and whether they were carers of people with dementia.

In 2004–05, nearly 33,000 carers received direct respite care services from the NRCP. Over four in ten were aged between 45 and 64 years and over one-third were aged 65 or over. The majority (78%) were women. Altogether, there were 59,342 carers assisted by Commonwealth Carer Respite Centres and 59,849 registered care recipients, with 17.2% of carers caring for someone with dementia (AIHW 2007b: Table 7.25).

**Table 5.3: National Respite for Carers Program, carers who received direct respite care services through Commonwealth Carer Respite Centres, 2004–05**

	Males	Females	Unknown	Persons	Males	Females	Unknown	Persons
	Number				Per cent			
Under 25	145	297	—	442	0.4	0.9	—	1.3
25–44	987	6,054	74	7,115	3.0	18.3	0.2	21.5
45–64	2,689	11,185	11	13,885	8.1	33.7	—	41.9
65 or over	3,501	8,218	6	11,725	8.2	19.2	—	35.4
<b>Total</b>	<b>7,322</b>	<b>25,754</b>	<b>91</b>	<b>33,167</b>	<b>22.1</b>	<b>77.7</b>	<b>0.3</b>	<b>100.0</b>

*Note:* The NRCP funds other types of services for clients besides direct respite care. Table excludes clients who received only services other than direct respite care and includes both carers who do and do not live with the care recipient.

*Source:* Unpublished data provided by Department of Health and Ageing for *Australia's welfare 2007*.

The NRCP MDS unit record data includes an extensive array of socio-demographic data for the carers and care recipients as well as information on the service episodes. A potential strength of this data collection is that it collects information about the carer-care recipient interaction in respect of all of the carer's care recipients (AIHW 2007b). Items collected by the NRCP include carer co-residency and relationship to the care recipient; the carer's need for support and the care recipients care needs; the care recipient's disability group and health condition; time spent caring; overall duration of the caring role; and the pattern of assistance received by the carer.

Additional data is being collected on the use of NRCP assistance in the 2008 Community Care Census which is a census of the program's clients over a 1-week period. This is expected to provide snapshot information on the amount of service provision, including respite care, and the characteristics of carers receiving assistance through this program and of the people they care for. Both carer and care recipient linkage keys are collected.

## Home and Community Care

HACC provides services to people with a moderate, severe or profound core activity limitation and their carers, and is not limited to the frail aged population. The AIHW requested access to all linked and unlinked HACC unit record data from all jurisdictions for financial years 2005-06 until 2009-10, including the unencoded statistical linkage key. This request covered a number of projects including this scoping study, however such permission was not granted so data included here are restricted to published data.

HACC MDS version 1 data (collected 2001-02 to 2004-05) records the provision of respite care against the carer's details and does not contain information about whether the carer lives with the care recipient. Information about carer co-residency is only recorded for the care recipient. Data in HACC MDS version 2 format records the care recipient and carer details in the one record and so can show both the provision of respite care and co-residency in relation to the care recipient as well as the carer. However, much of the data in the initial 2 years of MDS version 2 has been converted from version 1 format, and are not suitable for this type of analysis.

Other limitations of data converted from version 1 to version 2 format have been:

- the loss of information on the sex of the carer. In version 1 data the relationship specified was gender specific, for example, son was coded separately to daughter. In version 2 both are included in the one category and the sex of the carer has not been derived and retained in the carer sex field
- the loss of information on the receipt of carer payment (pension). The MDS version 2 dyad format contains only one field for government/pension benefit status. Where details of both care recipient and carer are provided this will be used for the care recipient rather than the carer.

In 2006-07 there were around 801,200 HACC clients of whom 38% had a carer<sup>5</sup> (DoHA 2008: Table A9). Just over 4% of clients used respite care services in that year, with an average of 71 hours of respite care in the year (around 1.4 hours per week) (Table 5.4). Comparison with data from previous years shows a decrease in both the proportion of clients with a carer, and the amount of respite care provided per year. The number of clients who received HACC respite care services more than doubled between 2004-05 and 2005-06 which coincides with the changeover from MDS version 1 to MDS version 2. This may be a true increase or may be associated with the change in reporting format or processing rules.

---

5. HACC clients include both carers and care recipients. The proportion of recipients having a carer has been calculated over the total number of clients as it is not possible here to remove carers from the denominator.

The majority of HACC carers who received respite care in 2006–07 were under 65 years of age (56%) and these younger carers had a higher average number of hours of respite care per year than older carers. There is no published information on the age of the care recipients.

As previously stated, where data on both carer and care recipient is provided in a HACC MDS version 2 unit record there will be the capacity for analysis by both carer and care recipient demographic characteristics and carer residency characteristics. There may also be capacity for analysis by the functional status of the care recipient. However, this is not possible for version 1 data that has been converted to version 2 format or records where details for both carer and care recipient have not been provided.

The HACC program also collects data on the use of centre-based day care. This is considered to be a service for the care recipient and is recorded against the care recipient details. The number of clients receiving centre-based day care was 80,802 in 2004–05, 82,842 in 2005–06, and 74,227 in 2006–07. Using MDS version 2 data, it will be theoretically possible to look at the use of centre-based day care services in relation to the carer.

**Table 5.4: Published data on the use of respite care by HACC clients, 2004–05 to 2006–07**

<b>Age of carer</b>	<b>Number of clients receiving respite care</b>	<b>Per cent of respite care recipients</b>	<b>Per cent of all HACC clients</b>	<b>Average hours of respite care per year</b>
<b>2004–05</b>				
0–64 years	11,271	68.5	1.5	104.1
65–69 years	1,109	6.7	0.1	80.2
70+ years	4,072	24.8	0.5	64.3
<i>Total respite care clients</i>	<i>16,452</i>	<i>100.0</i>	<i>2.2</i>	<i>92.6</i>
<b>Total HACC clients</b>	<b>744,197</b>	<b>—</b>	<b>100.0</b>	<b>—</b>
<b>2005–06</b>				
0–64 years	21,587	60.7	2.8	97.8
65–69 years	2,034	5.7	0.3	70.0
70+ years	11,901	33.5	1.5	51.2
<i>Total respite care clients</i>	<i>35,522</i>	<i>100.0</i>	<i>4.6</i>	<i>80.6</i>
<b>Total HACC clients</b>	<b>777,471</b>	<b>—</b>	<b>100.0</b>	<b>—</b>
<b>2006–07</b>				
0–64 years	19,282	55.7	2.4	89.8
65–69 years	1,843	5.3	0.2	56.8
70+ years	13,517	39.0	1.7	46.4
<i>Total respite care clients</i>	<i>34,642</i>	<i>100.0</i>	<i>4.3</i>	<i>71.1</i>
<b>Total HACC clients</b>	<b>801,209</b>	<b>—</b>	<b>100.0</b>	<b>—</b>

*Notes:*

1. Percentages may not add to total due to rounding.
2. The increase in respite care use coincides with the change from HACC MDS version 1 to version 2. This may be a real increase in service provision or associated with changes in data processing procedures.

Sources: DoHA 2006, DoHA 2007, DoHA 2008.

## Veterans' Home Care

Veterans' Home Care (VHC) provides a limited range of community care services (domestic assistance, safety-related home and garden maintenance, personal care, and respite care) to holders of DVA gold or white cards.

For eligible cardholders, in any one financial year, DVA may pay for up to 196 hours of in-home respite or 28 days of residential respite, or a combination of both. In addition to this, DVA offers episodes of up to 3 days (72 hours) of continuous emergency respite care, with a limit of three episodes per financial year (a maximum of 216 hours). In-home or emergency respite care is available to eligible cardholders who are either the care recipient or the carer.

The amount of in-home and emergency respite care provided is collected in the DVA data on the use of VHC program, which also contains information on approval for residential respite care.

In 2006–07, 7,615 veterans were approved to receive an average of 87 hours of in-home respite care and 83 were approved for an average of 38 hours of emergency respite care (Table 5.5). However the amount of respite care provided was an average of 69 hours in-home respite to 6,707 veterans and 32 hours of emergency respite care to 70 veterans. The combined average for these two types of respite care was 69.5 hours. It is clear from this information that not all of the approved respite care is used. It is not possible to tell from this data set alone whether this is a result of deterioration of the recipient's condition (possibly periods may be spent in hospital, the recipient may have moved to residential care or died). However, this question could be investigated using linked data.

The VHC annual statistical summary also reports on the amount of residential respite care approved. Nearly 6,400 eligible veterans were approved for an average of 19 days of residential respite care. However, information on the use of residential respite care is not available from this source. However, it would be included in the DoHA data on residential respite care and data linkage between these two data sources would facilitate more detailed analysis.

**Table 5.5: Approval and provision of respite care to eligible veterans and their carers, Veterans' Home Care Program, 2006–07**

Type of respite care	Approved			Provided		
	Number of VHC veterans	Total hours approved	Average approved hours	Number of VHC veterans	Total hours provided	Average hours provided
In-home respite	7,615	659,991	86.67	6,707	465,728	69.44
Emergency respite	83	3,123	37.63	70	2,232	31.89
<i>In-home and emergency respite combined</i>				6,736	467,960	69.47
Residential respite	6,384	868,811 (i.e. 126,687 days)	139.09 (i.e. 19.4 days)		Not known	

Note: 1 day of residential respite care is counted as 7 hours of respite care.

Source: DVA 2008.

Any investigation of the use of VHC services by care recipients with a carer must consider that veterans may also use other programs. Some veterans may choose to use HACC services in preference to VHC, and some types of assistance are not available through VHC. In particular, veterans receiving personal care from VHC but who require a higher level of personal care may receive this service through DVA Community Nursing services. Veterans may move between the two programs based on current need. The DVA Community Nursing data collection includes the

veteran's file number and surname and therefore it may be feasible for this data to be generated with a linkage key for the recipient. However the reference person is the veteran rather than the carer. The data set includes information on the existence of a carer, whether the recipient lives alone, some information on 'activities of daily living' capacity, and the hours of care provided by different types of nursing staff.

## **CACP and EACH recipients**

For frail older people who are assessed as eligible for residential aged care there are three types of community care packages available which include the provision of respite care. These are CACPs, EACH packages and EACH-Dementia (EACH-D) packages. CACPs are provided as the community care alternative to low-level residential aged care, while EACH and EACH-D packages are the alternative to high-level residential aged care. Consequently, recipients of EACH and EACH-D packages can be expected to be more dependent than CACP recipients.

A census of each of the first two types of packages was conducted in 2002. The 2002 EACH census was conducted at the end of the pilot phase of the program, while the program was still very small with only 288 recipients. EACH-D packages were not available until March 2006, and data on the provision of respite care to EACH-D package recipients will not be available until the results of the 2008 Community Care Census are released. However, it is possible to review EACH census data by dementia diagnosis.

Both the 2002 CACP and 2002 EACH censuses collected information on the existence of a carer, the co-residency of the carer and the relationship of the carer to the care recipient, as well as the amount of in-home respite care provided through the package. Information on whether the care recipient was accessing respite care from other programs was also collected. Both data collections recorded whether the care recipient was on leave from the program during the census week for the purpose of receiving respite care (AIHW 2004b) or alternative care including respite care (AIHW 2004a). Only the EACH census collected information on the use of residential respite care in the previous 12 months or since commencing on a package.

In contrast to HACC data, the reference person for these two collections was the care recipient not the carer, so any demographic data does not relate to the carer. However, information about the co-residency of the carer is available.

In the 2002 censuses, 1,144 CACP recipients and 108 EACH package recipients received respite care services. Table 5.6 looks at the use of in-home respite care by recipients of CACP and EACH package recipients who had a co-resident carer. This table shows the use of respite care provided as part of the package in combination with the use of respite care from other government-funded sources. Care recipients on both types of packages were more likely to use respite care services provided by the package provider (12% for CACP recipients and 47% for EACH recipients) than respite provided by other government programs (CACP 2%; EACH 9%). A small number of care recipients used both sources. A higher proportion of high-care package recipients (54%) used some form of in-home respite care than for low-care package recipients (14%).

Both census data sets also provided information about recipients who were on leave from the program during the census week:

- 1.6% (113) of CACP recipients with co-resident carers had leave from the program during the census week for 'alternative care' which includes respite care
- 5% (11) of EACH recipients with co-resident carers had leave from the program during the census week for respite care.

In addition, the EACH census collected information about the use of booked or emergency residential respite care in the previous 12 months (or since starting the package if less than 12 months); 12% (46/216) had used residential respite care in that time.

**Table 5.6: Use of package-provided respite care by care recipients with a co-resident carer, by use of respite care from other government programs during the census week, 2002 CACP and EACH censuses**

Use of package-provided respite care	CACP package recipients			EACH package recipients		
	Use of other sources of respite care		Total	Use of other sources of respite care		Total
	Yes	No		Yes	No	
	<b>Number</b>			<b>Number</b>		
Yes	24	820	844	15	87	102
No	144	6,260	6,404	5	109	114
<b>Total</b>	<b>168</b>	<b>7,080</b>	<b>7,248</b>	<b>20</b>	<b>196</b>	<b>216</b>
	<b>Per cent</b>			<b>Per cent</b>		
Yes	0.3	11.3	11.6	2.3	40.3	47.2
No	2.0	86.4	88.4	6.9	50.5	52.8
<b>Total</b>	<b>2.3</b>	<b>97.7</b>	<b>100</b>	<b>9.3</b>	<b>90.7</b>	<b>100</b>

### Administrative data for EACH and EACH Dementia recipients

Administrative data for CACP does not record any carer details for CACP recipients and records only the existence of a co-resident or non-resident carer for EACH and EACH-D recipients (Table 5.7). This information can be combined with the socio-demographic data for the care recipient that is collected by the administrative data set, but there is no information on the types or amount of assistance received. Currently, that type of information is only available in the census collections.

**Table 5.7: Availability and co-residence of a carer for EACH and EACH Dementia care recipients, 2006-07**

Type of care package	Co-resident carer	Non-resident carer	Total with a carer	No carer	Number of recipients with a carer	Proportion of carers who live with the care recipient
					Number	Per cent
EACH	71.1	18.9	90.0	10.0	2,699	79.0
EACH Dementia	76.7	18.1	94.8	5.2	827	80.9

Source: AIHW 2008.

### 2008 Community Care Census

Data collection for the Community Care Census was completed during 2008. This was a 1 week census including CACP, EACH and EACH-D recipients as well as NRCP clients. These data include a linkage key for both the carer and the care recipient, as well as information about the type and amount of assistance received by the care recipient, their need for assistance with activities and use of other government programs. In addition to the standard carer items which are collected for the main carer, the number of other informal carers was also collected. Collection

of the linkage key for the main carer enables carer linkage across programs. Data also include the age of the carer. Information on the use of residential respite care in the last 12 months was also collected for all three types of packages.

### **5.3 Why is respite care not being used?**

According to the ABS SDAC there are over 2 million carers and around half a million primary carers. Yet respite care, designed to primarily support carers in their role, is used by relatively small numbers of people.

Generally the main source of data about non-service use is SDAC. While SDAC looks at the reasons for not receiving respite care, it does not ask for reasons for not using specific types of respite care, so it is of limited value for service design.

Around 86% of co-resident primary carers had never used any form of respite care in the past. The most common main reason given was that they did not need it (61%), while for 13% the recipient did not want it and for 10% the carer did not. Only for 4% was the main reason the lack of suitability of available respite care services.

One possible reason for not using respite care may be the existence of a fall-back carer (Table 5.8). Just over half of respite care non-users (54%) had a fall-back informal carer, with 35% reporting that they did not. Carers reporting that they did not want this type of service were most likely to have a fall-back carer (61%), followed by those reporting that they did not need respite care services (56%). Existence of a fall-back carer was also fairly high among those who said that the main reason for not using respite care was that the recipient did not want it (49%).

In contrast, of those who did not use respite care because the available services were not suitable, 53% did not have a fall-back carer and 34% did.

Table 5.9 shows that the availability of a fall-back carer is negatively associated with the use of residential respite care. The proportion of recipients with a fall-back carer was lowest for those using residential respite care in the last 3 months (28%) and highest for those who had not used residential respite care in the last 3 months but had used respite care (61%). For those who had never used respite care, 54% had a fall-back carer.

Other possible reasons for differences in the use of residential respite care are the type of health or disability of the care recipient and of the carer. However, using SDAC it is not feasible to investigate this for specific types of respite care due to the small number of people in the sample with particular health conditions who use those services. A more suitable source of this type of analysis would be the Pathways in Aged Care (PIAC) cohort, which is larger and more robust. It includes both health conditions at assessment and use of residential respite care, but (at the time of writing) did not include other types of respite care.

**Table 5.8: Main reason for not using respite care, by the availability of a fall-back informal carer, for co-resident primary carers of recipients with a severe or profound core activity limitation, where the primary carer has never used respite care**

Main reason primary carer has never used respite care	Whether main recipient of care has a fall-back informal carer			Persons
	Has a fall-back informal carer	Does not have a fall-back informal carer	Don't know	
		<b>Number</b>		
Does not need service	95,900	57,100	19,500	172,500
Available services not suited to needs	3,800	6,000	1,600	11,400
Recipient does not want service	17,500	13,700	4,400	35,600
Carer does not want service	17,500	8,200	2,900	28,600
Other reason	17,000	14,300	2,000	33,200
<b>Total</b>	<b>151,800</b>	<b>99,300</b>	<b>30,200</b>	<b>281,300</b>
		<b>Column per cent</b>		
Does not need service	63.2	57.5	64.5	61.3
Available services not suited to needs	2.5	6.1	5.1	4.1
Recipient does not want service	11.5	13.8	14.4	12.7
Carer does not want service	11.6	8.3	9.4	10.2
Other reason	11.2	14.4	6.5	11.8
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>
		<b>Row per cent</b>		
Does not need service	55.6	33.1	11.3	100.0
Available services not suited to needs	33.6	52.7	13.6	100.0
Recipient does not want service	49.2	38.6	12.2	100.0
Carer does not want service	61.3	28.7	10.0	100.0
Other reason	51.1	43.0	5.9	100.0
<b>Total</b>	<b>53.9</b>	<b>35.3</b>	<b>10.7</b>	<b>100.0</b>

Source: Survey of Disability, Ageing and Carers, 2003.

Those who had never used respite care but who expressed a need for it were less likely to have a fall-back carer than those who said they did not need or want it (50% of the first group did not have a fall-back carer compared with 33% of the second group). Overall only 12% expressed an unmet need for respite care of any kind.

Around 11% of both groups (those who did and did not express a need for additional respite care) did not know whether they had a fall-back carer (Table 5.10). One situation where this may be the case is in circumstances where the normal carer is not certain whether an ad hoc carer, for instance a neighbour, would be available when needed.

**Table 5.9: Existence of a fall-back carer, by use of residential or other types of respite care for main recipient of care of co-resident primary carers**

Respite use	Whether main recipient of care has a fall-back carer			Total
	Has a fall-back informal carer	Does not have a fall-back informal carer	Don't know	
	<b>Number</b>			
Has used residential in the last 3 months	2,300	5,500	600	8,300
Has not used residential respite in last 3 months but has used respite care	24,800	14,300	1,500	40,500
Has never used respite care	167,000	109,800	34,700	311,600
<b>Total</b>	<b>194,000</b>	<b>129,600</b>	<b>36,800</b>	<b>360,500</b>
	<b>Per cent</b>			
Has used residential in the last 3 months	27.6	65.7	6.8	100.0
Has not used residential respite in last 3 months but has used respite care	61.1	35.2	3.7	100.0
Has never used respite care	53.6	35.2	11.1	100.0
<b>Total</b>	<b>53.8</b>	<b>35.9</b>	<b>10.2</b>	<b>100.0</b>

*Note:* Numbers have been rounded to the nearest 100 while percentages are calculated using the original estimates.

*Source:* AIHW analysis of ABS SDAC 2003

**Table 5.10: Need for further respite care services, by existence of a fall-back carer, for co-resident primary carers who had never used respite care services**

Need for additional respite care	Whether main recipient of care has a fall-back carer			Total
	Has a fall-back informal carer	Does not have a fall-back informal carer	Don't know	
	<b>Number</b>			
Does not need or want respite care	152,800	91,500	30,800	275,100
Needs more respite care	14,200	18,300	4,000	36,500
<b>Total</b>	<b>167,000</b>	<b>109,800</b>	<b>34,700</b>	<b>311,600</b>
	<b>Row per cent</b>			
Does not need or want respite care	55.6	33.3	11.2	100.0
Needs more respite care	38.9	50.2	10.9	100.0
<b>Total</b>	<b>53.6</b>	<b>35.2</b>	<b>11.1</b>	<b>100.0</b>
	<b>Column per cent</b>			
Does not need or want respite care	91.5	83.3	88.6	88.3
Needs more respite care	8.5	16.7	11.4	11.7
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*Note:* Numbers have been rounded to the nearest 100 while percentages are calculated using the original estimates.

*Source:* AIHW analysis of ABS SDAC 2003.

## Take-up of ACAT approvals and recommendations

Most administrative data only allow a perspective on those using the relevant service. The use of linked data in the PIAC cohort study gives us greater opportunity to explore non-service use by people assessed by an ACAT and with an approval and recommendation for specific types of care.

With funding from the NHMRC and the Dementia Collaborative Research Centre, the AIHW is analysing the pathways in aged care of people who had received an ACAT assessment in 2003-04. The linked database includes data from the ACAP MDS, the HACC MDS, DVA data on the use of the VHC program, DoHA data on the use of CACP, EACH and EACH-D programs, and the use of residential respite and permanent residential aged care. Linkage is not routine and requires approval from properly-constituted ethics committee(s) and data custodians. The linkage uses probabilistic matching primarily based on a common linkage key. The linked data provides longitudinal data on the use of aged care programs, and includes both the timing of each event and information about the client's personal circumstances at the time. It is a rich source for examining the diversity of care pathways, both in terms of the programs accessed and their use by individuals over time.

One limitation of this data is that the linkage is based on the care recipient and cannot include data that uses only the carer's linkage key. For this reason respite care services provided by HACC and NRCP are currently out of scope. Residential respite care which is recorded against the care recipient details can be linked and is in scope.

Some preliminary analyses in relation to respite care use have been carried out. These are:

- an analysis of the take up of residential respite care by people with dementia who have an approval for this type of care, including by carer status and country of birth
- logistic regression looking at factors affecting take up of residential respite care following ACAT approval for its use.

Of the 105,077 people with a completed ACAT assessment in 2003–04, 42,079 had at least one completed assessment which included approval for residential care. Of these, people with a carer had higher take-up rates than those without. For people with dementia, 37% of people with a carer used residential respite care within 12 months compared to 26% of those without a carer. For people without dementia the figures were 31% and 25% respectively. These results confirm the relatively low use of residential respite care even following an assessment and recommendation by a team of health professionals.

Logistic regression showed that people with a co-resident carer were more likely to take up residential respite care than people with a non-resident carer, and even more likely to take up residential respite care than people with no carer. In terms of carer relationship, only a care recipient whose carer was their daughter-in-law or son-in-law (both were included in the same category) were more likely to use residential respite care than a care recipient whose carer who was their daughter.

While administrative data for residential respite care contains socio-demographic information for the care recipient and dates of use, it does not contain any information about their carers. At present, linkage projects such as this are the only way to identify carer details for residential respite care users. This linkage project also has the capacity to identify concurrent use of different types of aged care services, and to provide some information about carer availability over time for some service recipients.

There is also no information on the existence of carers for residents of permanent residential aged care services, although some carers are known to provide substantial assistance to residents. This linked data cannot provide any information on the existence of carers for residents.

## 5.4 The case study and CNDR models

It is clear from this exploration that there is considerable variation in content of data collected by the different programs. Table 5.11 summarises the different scope of each of these earlier analysis tables. Despite the differences in scope, this exploratory analysis illustrates how the use of multiple data sets can throw light on a question of policy interest in a way which is not possible if analysis is restricted to a single data set. Data linkage also opens up new possibilities in the use of administrative data to explore non-use of services (not something usually possible with service by-product data), for example, take-up rates of ACAT recommendations for residential respite care.

Two of the possible CNDR models were effectively operational during the conduct of this case study analysis.

- A temporary Model 3-style physical data repository has been created for the PIAC cohort study. Unit record data was obtained from all relevant data custodians, along with ethics approvals and permission of data owners to link the data sets. The PIAC project has facilitated the development, testing and refining of a robust linkage methodology and junior researchers are now being trained in its use. Analysts with good knowledge of individual data sets and expertise in analysis of linked cohort data are currently investigating the data to produce policy-relevant results. The full benefits of this type of research can only be realised through this type of repository. The investment in data linkage expertise and analysis is considerable – the development of the linked database used for the PIAC cohort study required extensive ethics approvals and 2 years' work in developing, testing and refining the linkage methodology.
- A Model 1 style-metadata repository was essentially in operation for the remainder of the analysis in this case study. Time and resource constraints resulted in a decision to focus on collections where the data was readily available to the AIHW or already published. The AIHW did not have access to unit record data from each collection. For example, the AIHW was unable to obtain permission to use HACC unit record data for use in this scoping study, thus restricting the use of HACC data to published data. Similarly, time constraints and difficulty in obtaining NRCP data precluded efforts to obtain unit record data from that collection.

These time and resource restrictions are not uncommon in the conduct of research projects. Similarly denial of access to unit record data by data custodians also occurs for a variety of reasons. Access to the unit record data (and hence the full range of data items) would allow more informative analyses to be undertaken and comparable analysis to be undertaken within the restrictions imposed by the characteristics of the different data sets. A CNDR as per Model 1 has the highest risk of these data access restrictions, limiting the nature and quality of analysis possible. The inefficiencies associated with obtaining and analysing data under these conditions (including with little or no technical documentation) frequently erodes the time available for analysis and reporting.

While the report of this case study analysis has noted the difficulties associated with inconsistent data, the Model 1 approach provides no avenue for driving data improvements unless Model 1 is accompanied by an agreed governance structure involving all data owners and representatives of data users which has some responsibility for driving data developments.

**Table 5.11: Differences in scope of tables 5.4–5.10 presented in case study analysis**

Table	Program data					Census data					Survey data				
	5.2	5.3	5.4	5.5	5.7	5.7	5.7	5.6	5.6	5.6	5.8	5.8	5.9	5.9	5.10
Data set	ACAP	NRCP	HACC	VHC	EACH 2006–07	EACH 2006–07	EACH–D 2006–07	CACP 2002	EACH 2002	SDAC	SDAC	SDAC	SDAC	SDAC	SDAC
Reference person	Recipient	Carer	Carer	Recipient	Recipient	Recipient	Recipient	Recipient	Recipient	Carer	Carer	Carer	Carer	Carer	Carer
Basis	Assessments	Persons	Persons	Persons	Persons	Persons	Persons	Persons	Persons	Persons	Persons	Persons	Persons	Persons	Persons
Carers															
Co-resident	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
All carers	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	No	No	No	No	No
Type of respite care	Used at assessment and recommended			Approved only						Yes			Yes		
Residential respite															
In-home respite	Used at assessment and recommended		Yes	Approved and provided				Provided by packaged and other government funded programs	Provided by packaged and other government funded programs						
Emergency				Approved and provided											
Only any respite (includes CBDC)		Yes								Yes			Yes		
No respite										Yes			Yes		
Amount of respite		Not published	Average	Average				Available but not included	Available but not included		Yes		Yes		Yes
Other information															
Existence of a fall-back carer											Yes		Yes		Yes
Need for further respite care services															
Main reason for not using respite care															Yes

# 6 Conclusions and future directions

## 6.1 Usefulness of a CNDR

The concept of a Carers National Data Repository (CNDR) received strong support from many stakeholders in relation to its perceived value and usefulness.

The perceived benefits included drawing together the fragmented collections that include carer data. Carer data would become more visible, exposing both its limitations and gaps and highlighting possibilities for analysis. This would have the potential to encourage greater use of carer data, potentially building a community of skilled data users contributing to a stronger evidence base about carers. Revealing gaps and data limitations would support efforts to enhance data collection and reporting and encourage improvements to data quality and consistency.

Examining data from multiple sources can provide a different perspective on an issue under investigation. For example, according to SDAC most carers who do not use respite care either say they do not need it or do not want it. In contrast, the ACAP data shows many people who are assessed and are not using it do need respite care services and the PIAC study analysis shows that, even in those assessed as needing respite care services, take-up of ACAT approvals for residential respite is low. Similarly by comparing the use of respite care across programs, it is possible to compare the characteristics of those using the services and to gain a better insight into the type of respite care being used. Linkage of these data sets would permit more detailed analysis about concurrent service use of different respite care types, movement between these programs and the ways in which consumers construct their own 'packages' of care.

There are clear advantages with regard to fast and convenient access to data. Increasingly, administrative collections are including Statistical Linkage Keys (SLKs), and it is becoming more common to include these for both carer and recipient. One advantage of centrally located data sets is the ability to use the SLK to link data across various data collections (subject to appropriate ethics committee approvals), thus permitting cross-program analyses over time.

## 6.2 Scope of CNDR

A range of data sources collect at least some data about particular groups of carers. However, the usefulness of these data sources for carer data analysis varies widely, as does the data quality and availability and usefulness of technical documentation.

In the short term, if any data repository were to be established (using any of the three models), it would be sensible to limit the scope of the data holdings to those that have the richest and most useful data. These collections would include:

- ABS SDAC (the most comprehensive data collection about carers and the one recommended for use in deriving estimates of numbers of carers)
- ABS 2006 Population Census (for the ability to undertake small area analysis and analysis about carers in sub-populations of interest, such as Indigenous carers and carers from culturally and linguistically diverse groups)

- Carer Payment and Carer Allowance data
- CSTDA NMDS
- HACC MDS
- ACAP MDS
- CACP census (2002 and 2008 data)
- 2002 CACP and EACH census
- 2008 Community Care Census (CACP, EACH, EACH-D, NRCP).

## 6.3 Feasibility of CNDR

There are a number of issues affecting the feasibility of the three repository models described at the present time. The major constraints to feasibility arise from the potential cost of a repository and the uncertain levels of support by data custodians/owners. All three models would require significant resources – in the case of the metadata-only model there would be only modest benefits for this investment. Much of the potential benefit of a repository is centred on increased ease of access to and analysis of included data. Under this model, users would still be required to separately seek required data from a number of data custodians. Limitations to this model are evident in the case study analysis.

The decentralised virtual repository model faces similar constraints. Although access to data could be sought from a single portal, separate access to each collection would be required. This model would also require high stakeholder engagement to maintain. In preparing metadata and data in a consistent format for access, there would be complex technical issues to overcome. Furthermore, it is clear that some collections containing data about carers are subject to concerns for data quality, and further data development is needed. Data linkage protocols and arrangements would need careful consideration in the context of this model.

The physical data repository model is subject to these same limitations. Stakeholders have cited technical concerns, data quality concerns and data access concerns among reasons why such a model would be problematic. The major benefit of the third model is the capacity to include a regular monitored program of research and reporting and a locus of responsibility for driving data improvements. Arguably this function could be undertaken without the establishment of a data repository, although the ability to build increased capacity in the development and use of such data would be greatly enhanced by some repository arrangement.

## 6.4 Future directions

### Repository models

The establishment of a data repository under any of the three models discussed is not viable in the short term. The concerns of a number of data custodians/owners and potential cost, along with issues related to current data quality, suggest that it does not represent a sufficiently large improvement for the level of resourcing required. However, the potential benefits of a repository (particularly Model 3 and, to a lesser extent, Model 2) are such that the concept should not be dismissed altogether, but reviewed again in a couple of years' time.

## Analysis and reporting

In the shorter term, consideration should be given to funding a program of regular data analysis and reporting about carers. This would:

- draw upon multiple data collections
- make the carer data visible
- contribute to the development of a stronger evidence base about carers
- foster data development and analysis skills in relation to carer data
- support efforts to improve data quality and consistency
- support ongoing development of major data collections, such as the ABS SDAC.

A program of reporting could be developed which produced a mix of major reports on a regular basis (for example, a regular chapter on carers in the AIHW's biennial report *Australia's welfare* or following the release of the ABS SDAC every 6 years). In intervening time periods, separate smaller reports or data updates could be produced based on annual administrative data collections.

Some of the material contained in this scoping report can be viewed as the basis for a series of brief data updates in relation to carer data. This type of report would provide a point of reference for currently available data relating to carers, as well as information about data quality and ownership.

## Data development

Examination of currently available carer data reveals inconsistency and data quality issues. While data quality issues may be advanced within individual data sets, questions of consistency across data sets remain problematic and would limit the benefits of any sort of repository. Within the National Community Services Information Management Group (NCSIMG) strategic plan for 2005–2009, a review of existing collections relating to informal care is specified as a priority for action (AIHW 2005). The review would make clear recommendations on ways of improving the consistency of items used and coverage across collections. With the expiry of the current strategic plan and the development of an updated one, it is important that such a review remains a priority.

Other data development work could include the coordinated effort to introduce, over time, SLK linkage capability for carer details where this does not already exist, and the development of a set of 'minimum' data elements for carers to be introduced across collections to answer key policy questions, for example, carer labour force status.

# Appendix 1: Data mapping

Table A1.1: Administrative data collections

	HACC	CSTDA	ACAP	NRCP	CP/CA	EACH/EACH-D	VHC
Carer identification	Carer—existence of	Carer—existence of	Carer availability	Carer role	..	Carer availability	Lives alone/has a carer
Veteran identification	DVA card status	..	DVA entitlement	DVA card holder status	Veterans' Affairs payment type	DVA entitlement	Only applicable to veterans
Assistance provided	Primary type of assistance received (from HACC)	Activities and participation—support needs	Current assistance with activities Source of current assistance with activities	Informal support	What day to day care needs does the person you care for require? Do you personally provide (additional) care to this child/person because of their disability or medical condition?	Type of assistance received	Dependencies
Carer co-residency	Carer residency status	Carer—residency status	Carer co-residency status	Co-residency of carer	Does this child/person live with you?	Carer co-residency status	Lives alone/has a carer
Relationship of carer to care recipient	Relationship of carer to care recipient	Carer—relationship to service user	Relationship of carer to care recipient	Relationship of carer to care recipient	Relationship to carer Are you the parent or guardian of the child?	..	..
Carer age	Carer's date of birth	Carer—age group	..	Date of birth	Carer's date of birth	..	..
Carer sex	Carer's sex	Inferred from relationship	..	Sex	Carer's sex	..	..

(continued)

Table A1.1 (continued): Administrative data collections

	HACC	CSTDA	ACAP	NRCP	CP/CA	EACH/EACH-D	VHC
Carer CALD status	Carer's country of birth	..	..	Country of birth Main language other than English spoken at home	Country of birth (carer)	..	..
Carer Indigenous status	Carer's main language spoken at home	..	..	Indigenous status	Are you of Aboriginal or Torres Strait Islander origin? (carer)	..	..
Carer labour force status	Carer's Indigenous status	..	..	Paid employment participation	Are you currently undertaking and paid or voluntary work, study or training?	..	..
Carer source of income	..	..	..	Paid employment participation	..	..	..
Carer's location	Carer's Australian state/territory	..	..	Government pension/benefit status	Postcode—home address (carer)	..	..
	Carer's suburb/town/locality	..	..	Suburb/town/locality name	..	..	..
	Carer's postcode	..	..	Postcode	..	..	..
Care recipient disability	Functional status	Primary disability group	Body function impairments	Care recipient's primary care needs	What day to day care needs does the person you care for require?	Core activity limitations	Dependencies
		Other significant disability group(s)	Health condition	Care recipient's primary disability	Provide an assessment of the cognitive functions of the person you care for	Dementia status	
				Dementia			
				Challenging Behaviour			
				Care recipient's level of need			

(continued)

**Table A1.1 (continued): Administrative data collections**

	HACC	CSTDA	ACAP	NRCP	CP/CA	EACH/EACH-D	VHC
Care recipient disability (continued)					List the behaviours of the person you care for		
Care recipient age	Date of birth	Date of birth	Date of birth	Date of birth	Date of birth (care recipient)	Date of birth	..
Care recipient sex	Sex	Sex	Sex	Sex	Sex (care recipient)	Sex	..
Care recipient CALD status	Country of birth Main language spoken at home	Country of birth Main language other than English spoken at home	Country of birth Main language other than English spoken at home Proficiency in spoken English	Country of birth Main language other than English spoken at home	Country of birth (care recipient)	Country of birth Main language other than English spoken at home	..
Care recipient Indigenous status	Indigenous status	Indigenous status	Indigenous status	Indigenous status	..	Indigenous status	..
Care recipient labour force status	..	Labour force status	..	Paid employment participation	..	..	..
Care recipient source of income	Government pension/benefit status	Main source of income	..	Paid employment participation Government pension/benefit status	Does the person you care for receive payment from Centrelink or the Department of Veterans' Affairs?	..	..
Care recipient's location	Australian state/territory Suburb/town/locality Postcode	Service user postcode	Suburb/town/locality name	Suburb/town/locality name Postcode	Postcode	Postcode	..

**Table A1.2: Census data collections**

	<b>Census 2006</b>	<b>CACP Census</b>	<b>CCC</b>	<b>EACH Census</b>
Carer identification	Unpaid assistance to a person with a disability	Carer availability	Carer presence	Carer availability
Veteran identification	..	Veteran status	Pension status	Veteran status
Assistance provided	..	..	..	..
Carer co-residency	..	Carer co-residency status	Primary carer and care recipient living arrangements	Carer co-residency status
Relationship of carer to care recipient	..	Relationship of carer to care recipient	Relationship of primary carer to care recipient	Relationship of carer to care recipient
Carer age	Age	..	Primary carer's date of birth	..
Carer sex	Sex	..	Primary carer's sex	..
Carer CALD status	Country of birth Language spoken at home Proficiency in spoken English	..	Primary carer's country of birth Primary carer's main language spoken at home	..
Carer Indigenous status	Indigenous status	..	Primary carer's indigenous status	..
Carer labour force status	Labour force status	..	..	..
Carer source of income	..	..	Pension status	..
Carer's location	Available at a number of levels	..	Suburb State or territory Postcode	..
Care recipient disability	..	Core activity limitations Dementia status	Care recipient dementia/disability status	Core activity limitations Dementia status
Care recipient age	..	Date of birth	Care recipient's date of birth	Date of birth
Care recipient sex	..	Sex	Care recipient's sex	Sex
Care recipient CALD status	..	Country of birth	Care recipient's country of birth Care recipient's main language spoken at home	Country of birth
Carer recipient Indigenous status	..	Indigenous status	Care recipient's indigenous status	Indigenous status
Care recipient labour force status	..	..	..	..
Care recipient source of income	..	..	Pension status	..
Care recipient's location	..	Suburb/town/locality name Postcode	Suburb State or territory Postcode	Suburb/town/locality name Postcode

**Table A1.3: Survey data collections**

	GSS	HES/SH	MPHS	NHS	SDAC	SEARS	TUS
Carer identification	Carer status	Current weekly income from carer allowance Current weekly income from carer payment	Personal types of government pension/allowance received	Type of government pension/allowance received	Carer status Carer status derived using 1998 rules Whether household contains a primary carer Whether family contains a primary carer Primary carer populations	Unpaid activities in the last 4 weeks All types of government pensions/allowances received	Primary carer of person living in the household Carer to person living elsewhere
Veteran identification	..	Whether DVA gold card held (HES only) Whether DVA orange card held (HES only) Whether DVA pensioner concession card held (HES only) Whether DVA white card held (HES only) Current weekly income from servicepension (DVA) Current weekly income from war widow's pension (DVA)	Personal types of government pension/allowance received	Type of government pension/allowance received	Pensions, benefits or allowances received (all)	All types of government pensions/allowances received	Pension, benefit or allowances received (major)

(continued)

Table A1.3 (continued): Survey data collections

	GSS	HES/SIH	MPHS	NHS	SDAC	SEARS	TUS
Assistance provided	Type of support provided for other relatives living outside the household	..	..	..	Whether carer provides assistance with cognitive or emotional tasks	..	Self-care, mobility or communication assistance provided to person living elsewhere
					Whether carer provides assistance with communication tasks		Health care assistance provided to person living elsewhere
					Whether carer provides assistance with health care tasks		Home help, maintenance or meal preparation assistance provided to person living elsewhere
					Whether carer provides assistance with home maintenance or gardening tasks		Paperwork assistance provided to person living elsewhere
					Whether carer provides assistance with household tasks		Cognitive or emotional support assistance provided to person living elsewhere
					Whether carer provides assistance with meal preparation tasks		Transport assistance provided to person living elsewhere
					Whether carer provides assistance with mobility tasks		
					Whether carer provides assistance with private transport tasks		

(continued)

Table A1.3 (continued): Survey data collections

	GSS	HES/SH	MPHS	NHS	SDAC	SEARS	TUS
Assistance provided (continued)					Whether carer provides assistance with reading and writing tasks		
					Whether carer provides assistance with self-care tasks		
Carer co-residency	..	..	..	..	Derived variable	..	Primary carer of person living in the household
Relationship of carer to care recipient	..	..	..	..	Relationship of carer to recipient of care	..	Relationship of carer to main recipient living elsewhere
							Relationship of carer to recipient living in household
Carer age	Age group	Age	Age	Age of person (years)	Age	Age group (years)	Age of person
Carer sex	Sex	Sex	Sex	Sex of person	Sex	Sex	Sex of person
Carer CALD status	Country of birth	Country of birth	Country of birth	Country of birth	Country of birth	Country of birth	Country of birth
	Main language other than English spoken at home		Main language spoken at home				Country of birth of mother
	Proficiency in spoken English						Country of birth of father
							Year of arrival in Australia
							First language spoken

(continued)

Table A1.3 (continued): Survey data collections

	GSS	HES/SH	MPHS	NHS	SDAC	SEARS	TUS
Carer CALD status (continued)							Main language spoken at home
Carer Indigenous status	..	..	..	Indigenous status	..	..	Proficiency in spoken English
Carer labour force status	Labour force status	Labour force status	Labour force status	Labour force, full-time/part-time status	Labour force status and full-time/part-time status	Labour force status	Labour force status and full-time or part-time status
Carer source of income	Principal source of personal income	Comprehensive income source data available	All sources of personal income Principal source of personal income	..	Main source of cash income	Main source of current income	Principal source of cash income
Carer's location	State or territory of usual residence Capital city/balance of state Remoteness area Section of state	Remoteness area Section of state State or territory Statistical local area Urban Centre Locality	State or territory of usual residence Capital city/balance of state Remoteness area	State/territory Capital city/ rest of state Section of state Remoteness area	Section of state State or territory of usual residence	State or territory of usual residence Area of usual residence Region of usual residence	Capital city/balance of state Section of state State or territory Remoteness
Care recipient disability	Disability or long-term health condition Disability type	..	..	..	Main disability of recipient(s) of care Main condition of recipient(s) of care	..	Disability status Whether has a sight, hearing or speech disability Whether has a physical disability Whether has an intellectual disability Whether has a psychological disability

(continued)

Table A1.3 (continued): Survey data collections

	GSS	HES/SH	MPHS	NHS	SDAC	SEARS	TUS
Care recipient disability (continued)							Whether has an other disability
Care recipient age	Age group	..	..	..	Age of recipient(s) of care	..	Age of person
Care recipient sex	Sex	..	..	..	Mapped sex of recipient(s) of care	..	Sex of person
Care recipient CALD status	Country of birth	..	..	..	Country of birth	..	Country of birth
	Main language other than English spoken at home						Country of birth of mother
	Proficiency in spoken English						Country of birth of father
							Year of arrival in Australia
Care recipient Indigenous status	..	..	..	..	..	..	First language spoken
Care recipient labour force status	Labour force status	..	..	..	Labour force status and full-time/part-time status	..	Main language spoken at home
							Proficiency in spoken English
							..
Care recipient source of income	Principal source of personal income	..	..	..	Main source of cash income	..	Labour force status and full-time or part-time status
							Whether has employment restrictions
							Principal source of cash income

(continued)

	<b>GSS</b>	<b>HES/SIH</b>	<b>MPHS</b>	<b>NHS</b>	<b>SDAC</b>	<b>SEARS</b>	<b>TUS</b>
<b>Care recipient's location</b>	State or territory of usual residence Capital city/balance of state Remoteness area Section of state	..	..	..	Section of state State or territory of usual residence	..	Capital city/balance of state Section of state State or territory Remoteness

# Appendix 2: Review of current provisions and policies<sup>6</sup>

## Australian and state/territory-funded programs

### **Aged Care Assessment Program (ACAP)**

The Aged Care Assessment Program is jointly funded by the Australian Government and the states and territories. Assessment and approval by an Aged Care Assessment Team (ACAT) is mandatory for admission to residential care, to receive a Community Aged Care Package (CACP), to receive an Extended Aged Care in the Home (EACH) package, or for admission to residential respite. ACATs also refer people to community services.

**Definition of a carer:** 'Someone such as a family member, friend or neighbour, excluding paid or volunteer carers organised by formal services (including paid staff in funded group houses), who has been identified as providing regular and sustained care and assistance to the client without payment other than possibly a pension or benefit.'

**Target population/eligibility:** Older people who are having difficulty living at home.

**Services provided:** ACATs are required to conduct a holistic assessment of a client's care needs, taking into account the physical, psychiatric and social needs of frail older people, including their rehabilitation potential, in order to help them choose the most appropriate services to meet their needs. ACATs can approve eligibility for entry into residential aged care in either low-level care or high-level care; give information about residential aged care and home care services in a client's area; help arrange special respite care; and approve eligibility for a package of community care. ACAT approvals are valid for 12 months. If a person's care needs change to the extent that a different level or type of care is required within a 12-month period they may be reassessed.

**Data collected:** A minimum data set is collected by all jurisdictions and received and analysed by the ACAP National Data Repository held at The Lincoln Centre for Research on Ageing at La Trobe University. The MDS includes items on carer availability, carer co-residency status and relationship of the carer to the care recipient.

---

6. Correct as at 30 June 2008.

## **National Respite for Carers Program (NRCP)**

The NRCP funds direct and indirect respite care options, offering respite care in a range of accommodation settings, including day centres, host homes, overnight cottages and in-home respite services. These services can be arranged by Commonwealth Respite and Carelink Centres.

**Definition of a carer:** 'A person such as a family member, friend or neighbour, who provides regular and sustained care and assistance to another person without payment other than a pension or benefit.'

**Eligibility:** Access to respite care is based on priority and need. For respite care in the home or in a day care centre, the respite service provider, or the Commonwealth Carer Respite Centre will assess eligibility. The amount of care received will depend on needs, eligibility, and the availability of respite care services.

To receive respite care in an aged care home requires assessment by an Aged Care Assessment Team, except in emergency situations.

**Target population:** Carers of older people, people needing palliative care and people with disabilities.

**Services provided:** Direct respite consists of the types of respite care arranged where the primary purpose is meeting the needs of carers by the provision of a break from their caring role. A service or multiple services are arranged to ensure that the carer has a relief carer for the person for whom they are the primary carer. Indirect respite includes services that are intended to indirectly assist the carer. The carer remains the primary focus although the services provided are for the person being cared for. It includes domestic assistance, social support, meals and nursing/personal care and showering assistance.

**Data collected:** NRCP data set maintained by DoHA. The NRCP collects information about carers assisted by the program and the carer-care recipient interaction in respect of all the carer's care recipients.

## **Home and Community Care Program (HACC)**

The HACC Program is a joint Australian Government, state and territory initiative under the auspices of the *Home and Community Care Act 1985*. The program provides funding for services which support people who are frail aged, younger people with disability and their carers, who live at home and whose capacity for independent living is at risk or who are at risk of premature or inappropriate admission to long-term residential care.

**Definition of a carer:** 'A person such as a family member, friend or neighbour, who provides regular and sustained care and assistance to another person without payment other than a pension or benefit.'

**Eligibility:** Eligibility for services is based on frailty related to impaired functional capacity. Impaired functional capacity can be denoted by difficulties in tasks of daily living and the need for assistance or supervision due to an ongoing moderate, severe or profound functional disability. 'Tasks of daily living' include dressing, preparing meals, house cleaning and maintenance, and using public transport.

**Target population:** '(A) People in the Australian Community who, without basic maintenance and support services provided under the scope of the National Program, would be at risk of premature or inappropriate long term residential care, including older and frail people with moderate, severe or profound disabilities; younger people with moderate, severe or profound disabilities. (B) The unpaid carers of people assessed as being within the National Program's 'target population'.

**Services provided:** HACC services can be offered to people in: their own homes; retirement villages, independent living units, caravan parks, self-care units, boarding houses, group/community housing; or unstable housing circumstances. Service or 'assistance types' include: allied health care, assessment, case management, centre-based day care, client care coordination, counselling/support/info and advocacy, domestic assistance, formal linen service, home maintenance, home modification, meals, nursing care, other food services, personal care, provision of goods and equipment, respite care, social support, transport.

**Data collected:** Collection of data for an MDS has occurred since January 2001 with 4 Annual Bulletins published to date: 2001-02, 2002-03, 2003-04 and 2004-05.

## **Community Aged Care Packages (CACP)**

Community Aged Care Packages (CACPs) are individually planned and coordinated packages of care tailored to help older Australians remain living in their own homes. They are funded by the Australian Government to provide for the complex care needs of older people.

**Definition of a carer:** 'Someone such as a family member, friend or neighbour, excluding paid or volunteer carers organised by formal services (including paid staff in funded group houses), who has been identified as providing regular and sustained care and assistance to the client without payment other than possibly a pension or benefit.'

**Eligibility:** To receive a CACP, a client must be assessed by an Aged Care Assessment Team (ACAT) as requiring low-level care. If CACPs are available in a client's area, they have been assessed as needing low-level care, and expressed a preference to be cared for in their home, then they may be offered a CACP package of care.

**Target population:** CACPs are targeted to frail older people, aged 70 years and over or 50 years and over for Aboriginal and Torres Strait Islander people, living in the community, who require provision of services because of their complex care needs. These people would otherwise be assessed as eligible for at least low-level residential care.

**Services provided:** A CACP provides a package of assistance managed by a care coordinator, who manages the complex care needs of the recipients and arranges provision of the following types of assistance: personal care, domestic assistance, social support, assistance with meal preparation and other food services, respite care, rehabilitation support, home maintenance, delivered meals, linen services and transport.

**Data collected:** Data held on the Aged and Community Care Management Information System (ACCMIS). ACCMIS is a data repository that contains information gathered through a number of instruments, particularly the Aged Care Client Record and The Provider Claim Form. The Aged Care Client Record is a form used for the assessment and approval of a care recipient for residential aged care, a CACP or EACH/EACH-D package (the record is valid for 12 months from the date of approval). The Provider Claim Form is completed by the service provider for claiming the Community Care Subsidy that is payable for the service for a payment period. This ongoing data does not include information about carers.

### **Extended Aged Care at Home (EACH)**

The EACH program is intended as a community alternative for older people who would otherwise need high-level residential care.

**Definition of a carer:** 'Someone such as a family member, friend or neighbour, excluding paid or volunteer carers organised by formal services (including paid staff in funded group houses), who has been identified as providing regular and sustained care and assistance to the client without payment other than possibly a pension or benefit.'

**Eligibility:** Recipients require approval from an ACAT to access an EACH package.

**Target population:** This package is targeted to 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. These people would otherwise be assessed as eligible for high-level residential care.

**Services provided:** EACH packages provide a similar range of care services as CACPs with the addition of nursing and allied health care services.

**Data collected:** Data held on the Aged and Community Care Management Information System (ACCMIS). ACCMIS is a data repository that contains information gathered through a number of instruments, particularly the Aged Care Client Record and The Provider Claim Form. The Aged Care Client Record is a form used for the assessment and approval of a care recipient for residential aged care, a CACP or EACH/EACH-D package (the record is valid for 12 months from the date of approval). The Provider Claim Form is completed by the service provider for claiming the Community Care Subsidy that is payable for the service for a payment period. This ongoing data includes information about carers.

### **Extended Aged Care at Home Dementia (EACH-D)**

EACH-D provides coordinated and managed packages of care to frail older people with dementia who experience behaviours of concern.

**Eligibility:** Eligible care recipients will have complex high-care needs associated with their dementia, require high-level residential care, but have expressed a preference to live at home and are able to do so. ACAT assessment and approval is required to access EACH-D.

**Target population:** This package is targeted to people aged 70 years and over or 50 years and over for Aboriginal and Torres Strait Islander people, with dementia, who experience behaviours of concern that affect their ability to live independently.

**Services provided:** A key feature of EACH-D is the provision of individually tailored packages of care to approved care recipients that are planned and managed by an Approved Provider. Service approaches and strategies can include, but are not limited to, the following: linkages to specialists to assist in the management of behaviours of concern relating to dementia; additional assistance during periods of specific need, for example with 'sundowning' (that is, when a person with dementia is particularly restless, confused and insecure in the afternoons and evenings); innovation, flexibility and responsiveness in meeting the changing needs of care recipients; personal care including continence care; specialist nursing care; additional supports to assist with activities of daily living associated with cognitive deficits; assistance with meals; and home help and maintenance.

**Data collected:** Data held on the Aged and Community Care Management Information System (ACCMIS). ACCMIS is a data repository that contains information gathered through a number of instruments, particularly the Aged Care Client Record and The Provider Claim Form. The Aged Care Client Record is a form used for the assessment and approval of a care recipient for residential aged care, a CACP or EACH/EACH-D package (the record is valid for 12 months from the date of approval). The Provider Claim Form is completed by the service provider for claiming the Community Care Subsidy that is payable for the service for a payment period. This ongoing data includes information about carers.

## **Residential Respite Care**

Residential respite care provides short-term accommodation and care in residential aged care homes on a planned or emergency basis.

**Eligibility:** An ACAT approval is required to access residential respite care and an approval remains valid for 12 months.

**Services provided:** A person with a valid ACAT approval for residential respite care may use up to 63 days of respite care in a financial year, which can be taken in 'blocks', for example, 1 or 2 weeks at a time.

**Data collected:** Data held on the Aged and Community Care Management Information System (ACCMIS). ACCMIS is a data repository that contains information gathered through a number of instruments, particularly the Aged Care Client Record and The Provider Claim Form. The Aged Care Client Record is a form used for the assessment and approval of a care recipient for residential aged care, a CACP or EACH/EACH-D package (the record is valid for 12 months from the date of approval). The Provider Claim Form is completed by the service provider for claiming the Community Care Subsidy that is payable for the service for a payment period. This ongoing data does not include information about carers.

## **Australian and State/Territory Agreement**

### **Commonwealth State/Territory Disability Agreement (CSTDA)**

The CSTDA provides a national framework for the delivery, funding and development of specialist disability services for people with disabilities.

**Services provided:** There are seven service groups under the CSTDA that offer specialist support for people with disability. These groups are accommodation support services; community support services; community access services; respite services; employment services; advocacy, information and print disability services; and other support services.

**Data collected:** National data on services provided under the CSTDA are collected in a National Minimum Data Set. The AIHW collates data on the MDS and provides analyses in annual reports.

**Data on the CSTDA MDS related to carers:** The CSTDA collects information on the carers of people with a disability. Information is collected about the existence of an informal carer, whether the carer is a primary carer and whether the carer is co-resident with the care recipient.

## Payments and allowances

### Carer Payment

Carer Payment provides income support to people who, because of the demands of their caring role, are unable to support themselves through substantial workforce participation.

**Eligibility:** In the home of the person being cared for, you provide constant care for:

- a person aged 16 or over with a severe disability or medical conditions OR
- an adult with moderate care needs and supervision of their dependant child if this child is under 6 or 6-16 and receiving Carer Allowance OR
- a child under 16 with a profound disability or medical condition and extremely high care needs OR
- two or more children under the age of 16 with severe disabilities or medical conditions that together have extremely high care needs AND
- you meet the income and assets tests AND
- you and the person you care for qualify under an International Agreement or are Australian residents, that is both of you are living in Australia and are one of the following: an Australian citizen; a permanent visa holder; a New Zealand citizen who was in Australia on 26 February 2001 or for 12 months in the 2 years immediately before that date, or who was granted protected status before 26 February 2004 AND
- you have been in Australia as an Australian resident for at least 104 weeks (some exceptions) AND
- the total hours you work, study, or train including voluntary work and travel time do not exceed 25 hours per week.

The person/s you care for needs to:

- be receiving a payment from Centrelink, a Veterans' Affairs Service Pension or Partner Service Pension OR be unable to receive any of these payments because they have not lived in Australia long enough to qualify AND/OR
- meet the special care receiver income & assets limits
- a doctor's or health professional's report.

**Entitlements available:** Eligible clients may receive:

- a fortnightly Carer Payment (income & assets tested): Basic rates- single \$537.70; couple \$449.10 each (since July 2000, has included a supplement. It is currently single \$18.50; couple \$15.50 each).
  - > paid fortnightly to bank or credit union account
  - > partnered rate payable to one member of a couple if partner is not receiving a pension, benefit or allowance
  - > may be paid for up to 63 days in a calendar year during a period of respite, either in Australia or outside Australia
- a pensioner concession card
- Pharmaceutical Allowance.

**Data collected:** Administrative payment system data.

## **Carer Allowance**

Carer Allowance is a supplementary payment available to parents or carers who provide daily care and attention for adults or children with a severe disability, medical condition or who are frail aged. Carer Allowance is not income and asset tested and may be paid on top of wages, Carer Payment, or other payments, such as Age Pension.

**Eligibility:** You may receive Carer Allowance if:

- you are looking after a child or an adult with a severe disability or medical condition who needs a lot of additional care and attention AND
- you live with the child you are caring for OR
- you provide care for an adult in either your home or the home of the person you care for AND
- you and the person you care for qualify under an International Agreement or are Australian residents, that is both of you are living in Australia and are one of the following: an Australian citizen; a permanent visa holder; a New Zealand citizen who was in Australia on 26 February 2001 or for 12 months in the 2 years immediately before that date, or who was granted protected status before 26 February 2004

You need a doctor's or health professional's report to help establish eligibility.

**Entitlements available:** Eligible clients may receive:

- if you are caring for a child under 16: a fortnightly Carer Allowance plus a health care card
  - > you can get Carer Allowance for more than one child
  - > if you have two children with disabilities and the children do not individually qualify for Carer Allowance, but together create a substantial caring responsibility, you may still be entitled to a single rate of Carer Allowance
- if you are caring for an adult aged 16 or over: a fortnightly Carer Allowance
  - > you can get Carer Allowance for up to two adults
- rate: \$98.50 per fortnight
  - > in certain circumstances, two carers may share one Carer Allowance payment
- \$1000 to be paid annually to a person receiving Carer Allowance on 1 July for each child being cared for under 16 years of age.

**Data collected:** Administrative payment system data.

## National policy initiatives

### The Way Forward

The Way Forward is a policy initiative of the Australian Government. The initiative aims to improve the community care system through reducing complexity and creating greater consistency. The focus of reforms is on programs funded through the Australian Government Department of Health and Ageing.

#### Action areas relating to carers:

##### Streamlining Australian Government-funded programs

- The Australian Government will develop a single contract that combines the functions of the Commonwealth Carer Resource Centres and the Carer Information and Support Program for the provision of specialist information, support and advice on carer identified issues.
- The Australian Government will, following the stocktake of respite services funded under NRCP, require these respite services to adopt common program arrangements consistent with other community care programs, in terms of assessment of eligibility, accountability, quality assurance and data collection.
- The following program alignment will be investigated further in 2004–05:
  - Streamlining contracts for services currently provided by the three community care peak bodies – Carers Australia, Alzheimer’s Australia and the Continence Foundation of Australia.

##### Support for carers

Carers Package – this measure, which will be delivered through the Department of Family and Community Services, provides \$461 million for additional support to carers.

The Carers Package includes: an extension of the Carer Allowance to carers who do not live with the people for whom they provide substantial levels of care; a one-off Carer Bonus of \$1,000 to eligible recipients; and respite services for young carers and for parents of people with a disability in prescribed circumstances.

##### Easier access to services

The Australian Government will work with state and territory governments to collaboratively develop intake assessment for HACC services within the national framework that also encompasses other community care programs. The Australian Government will fund the development of a nationally consistent intake assessment tool, encompassing the HACC nine-item dependency tool. The tool will, at a minimum, incorporate eligibility assessment for the HACC Program, the National Respite for Carers Program and the Day Therapy Centres Program. Appropriate pilot testing will be a key feature of this development work.

## **Securing the Future of Aged Care for Australians**

### **Action areas relating to carers:**

#### **More and better community care**

- More respite available for carers assisting the frailest older people who live at home.
- More money will be available for the National Respite for Carers program. Carers will benefit from the provision of additional respite hours – an extra 100,000 days of respite over 4 years – under the *Additional High Care Community Respite* initiative.
- More accessible respite services will be created in which older people can be temporarily cared for at home, an overnight cottage or a community-based respite centre to give the carer a break.

# References

- ACAP NDR (Aged Care Assessment Program National Data Repository) 2007. Aged Care Assessment Program National Data Repository: minimum data set report, Annual Report 2005–06. Melbourne: La Trobe University.
- Access Economics 2005. The economic value of informal care. Canberra: Access Economics.
- Adler G, Kuskowski M, & Mortimer J 1995. Respite use in dementia patients. *Clinical Gerontologist* 15:17–30.
- ABS (Australian Bureau of Statistics) 2006. 2901.0 - Census Dictionary, 2006 (Reissue): Contents <<http://www.abs.gov.au/AUSSTATS/abs@.nsf/0/4072E0FDC5B29214CA2572B300208A26?opendocument>> Viewed 20 July 2009.
- AIHW (Australian Institute of Health and Welfare) 2004a. Community Aged Care Packages census 2002. Aged care statistics series no. 17. Cat. no. AGE 35. Canberra: AIHW.
- AIHW 2004b. Extended Aged Care at Home census 2002: a report of the May 2002 Census prepared for the Australian Government Department of Health and Ageing. Aged care statistics series no. 15. Cat. no. AGE 33. Canberra: AIHW.
- AIHW 2005. National Community Services Information – A Strategic Plan 2005–09. Cat. no. AUS 68. Canberra: AIHW.
- AIHW 2007a. Australia's welfare 2007. Australia's welfare no. 8. Cat. no. AUS 93. Canberra: AIHW.
- AIHW 2007b. Dementia in Australia: national data analysis and development. Cat. no. AGE 53. Canberra: AIHW.
- AIHW 2008. Aged care packages in the community 2006–07: a statistical overview. Aged care statistics series no. 27. Cat. no. AGE 57. Canberra: AIHW.
- AIHW: Karmel R 2006. The ins and outs of residential respite care. AIHW bulletin no. 43. Cat. no. AUS 80. Canberra: AIHW.
- Barrett T 2005. *Roughing it in the bush – carers in rural and remote Western Australia: their needs and experiences*. The University of Western Australia.
- Berg-Weger M & Tebb S 2004. Conversations with researchers about family caregiving: trends and future directions. *Generations* 27:9–16.
- Bittman M, Fisher K, Hill P, Thomson C, & Thompson D 2004. Identifying isolated carers: contacting carers with unmet needs for information and support. Final report for the Australian Research Council Linkage Grant Project. Kensington: Social Policy Research Centre, University of NSW.
- Cardona B, Chalmers S, & Neilson B 2006. *Diverse strategies for diverse carers – the cultural context of family carers in NSW*. Sydney: Centre for Cultural Research, University of Western Sydney.
- Carers Australia 2004. *Research, policy and advocacy*. Place of publication: Publisher. Viewed 10 October 2007, <[www.carersaustralia.com.au/index.php?option=com\\_content&task=view&id=25&Itemid=102](http://www.carersaustralia.com.au/index.php?option=com_content&task=view&id=25&Itemid=102)>.

Department of Health and Ageing (DoHA) 2006. Home and Community Care Program Minimum Data Set, 2004-05 annual bulletin. Canberra: DoHA. Viewed date? September 2008, <[http://www.health.gov.au/internet/wcms/publishing.nsf/Content/hacc-pub\\_mds\\_sb.htm](http://www.health.gov.au/internet/wcms/publishing.nsf/Content/hacc-pub_mds_sb.htm)>.

DoHA 2007. Home and Community Care Program Minimum Data Set, 2005-06 annual bulletin. Canberra: DoHA. Viewed date? September 2008, <[http://www.health.gov.au/internet/wcms/publishing.nsf/Content/hacc-pub\\_mds\\_sb.htm](http://www.health.gov.au/internet/wcms/publishing.nsf/Content/hacc-pub_mds_sb.htm)>.

DoHA 2008. Home and Community Care Program Minimum Data Set, 2006-07 annual bulletin. Canberra: DoHA. Viewed date? September 2008, <[http://www.health.gov.au/internet/wcms/publishing.nsf/Content/hacc-pub\\_mds\\_sb.htm](http://www.health.gov.au/internet/wcms/publishing.nsf/Content/hacc-pub_mds_sb.htm)>.

Dow B, Haralambous B, Giummarra M & Vratsidis F 2004. What carers value - review of carer literature and practice. Melbourne: Victorian Government Department of Human Services.

DVA 2008. Veterans' Home Care annual statistical summary 2006-2007. Canberra: DVA. Viewed date? September 2008, <<http://www.dva.gov.au/health/homecare/mainvhc.htm>>.

Gray M & Hughes J 2005. Caring for children and adults - differential access to family-friendly work arrangements. *Family Matters* 70:18-25.

Hales C 2007. Crisis or commotion? An objective look at evidence on caregiving in families. *Family Matters* 76:18-23.

Hughes J 2007. Caring for carers: the financial strain of caring. *Family Matters* 76:32-3.

Kosloski K & Montgomery R 1995. The impact of respite use on nursing home placement. *The Gerontologist* 35:67-74.

Taskforce on Care Costs (TOCC) 2007. TOCC reports - key findings. Place of publication: Publisher. Viewed 18 October 2007, <<http://www.tocc.org.au/reports.html>>.