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## Summary of the schema used in this report to classify the strength of the evidence

1. **Well-supported practice** – evaluated with a prospective randomised controlled trial
2. **Supported practice** – evaluated with a control group and reported in a peer-reviewed publication
3. **Promising practice** – evaluated with a comparison group
4. **Acceptable practice** – evaluated with an independent assessment of outcomes, but no comparison group (e.g., pre- and post-testing, post-testing only, or qualitative methods) or historical comparison group (e.g., normative data)
5. **Emerging practice** – evaluated without an independent assessment of outcomes (e.g., formative evaluation, service evaluation conducted by host organisation)
6. **Profiles of carer population** (e.g., routine data)
7. **Eligibility for support** (e.g., legislation, policy)
8. **Carers' views** (e.g., surveys, interviews)
9. **Expert opinion** (e.g., peak bodies, government policy)
10. **Economic evaluation** (including service utilisation studies)

## Executive summary

This report on *Effective Caring* aims to identify the needs of carers including the factors that sustain carers in their caring role, identify effective interventions and to develop and set out a prioritised research agenda in this area. The *Effective Caring* project has been carried out in several stages:

- An international literature review
- A workshop of key service delivery and academic experts aiming to identify:
  - Priorities for improving routine practice in carer support networks
  - Priorities for building a coherent research and development agenda
- This final report that incorporates both the literature review and the outcomes of the workshop.

This report addresses what has been gathered through a review of Australian and international academic and practice literature, and a concurrent analysis of policy and practice in Australia. The findings are designed to provide an evidence base, both for carer interventions and for a research agenda that complements and extends the work already done on understanding and assessing carers' needs. The findings are presented in two volumes, one containing the background and methods and the findings set out as a synthesis of the evidence, and a second volume of attachments containing the detailed description of the material found in the search strategies. The national legislative and policy context shows a progressive growth of sophistication in the way that carers and their roles are understood, from marginal to more central in policy formation, and from a generalised part of the community care 'integration problem', to being treated as a segment of the population and a focus in the community care sector to be understood in its own right.

The continuation of this trend towards a more central role for carers appears inevitable and has a number of implications. Within the specific carer support programs there is likely to be continued development and expansion of the National Respite for Carers Program (NRCP) and State and Territory based carer support programs. The focus on carer support interventions within the mainstream of service provision implies a more consistent approach to carers across the range of human service programs. If that likely growth is underpinned by coherent and effective intervention strategies, then the essential next step is a carefully prioritised and sequenced program of research and development.

From the review carried out for this project the States and Territories and advocacy groups point out there is clearly scope for work within the carer support sector toward a clearer division of labour and combined effort, a focus on restorative and rehabilitation strategies, and providing a common a base for training and support for carers and workers in the community care sector. If improving the focus on carer support interventions is to avoid fragmentation and to mesh with the wider system reform agendas, then that implies a consistent approach (at the very least): between sub-programs within the NRCP; the systems of income support for carers; the disability sector; and State and Territory based carer support programs.

### ***The evidence on the needs of carers***

There is a sound body of literature on carers in Australia from population surveys by the Australian Bureau of Statistics, reports by the Australian Institute of Health and Welfare, as well as studies of specific carer needs and support issues by research groups and advocacy bodies. There are also assessment tools that can be used to describe a profile of carers seeking respite and other community care services. However, a research and development agenda and useful framework for building more effective practices in carer support do not come about by adding up the sum total of all that is known about carers and their needs. The application of some organising principles, a

measure of useful theory, and the careful use of evidence on what works best for supporting carers should guide the setting of priorities for a carer support diverse sector.

The majority of reviews of the needs of carers cover the carers of people with dementia. Other reviews cover cancer and the palliative care phase of illnesses, chronic conditions, life-long disabilities and mental illness. There are no major differences highlighted in the review literature between the carers of different types of care recipients beyond some expected differences in the need for support and practical assistance arising from facing the emotional pressures of dealing with challenging behaviours in people with dementia. The experience of bereavement for carers facing the death of the care recipient has its understandable impact and for those dealing with complex technical tasks in the course of ongoing caring activities for the chronically ill there is a need for practical assistance and support.

The types of needs that are described within the different reviews within the sub-sets of types of carers, shows the commonality in the types of needs, and the range of the measures that were reported in the literature to describe those needs. This literature also shows a growing recognition in the past decade, in terms of social policy and administrative and program focus, of the role of carer support. That in turn indicates the need for building a common understanding across services, programs, departments and the academic community of the role of carer support and how this might most effectively be strengthened.

### ***The evidence on the effectiveness of carer interventions***

Little is known about the effective 'dose' of carer support interventions or the best time for their delivery. Evaluation studies in community care settings often fail to provide full details about the intervention, making it difficult to judge what was actually delivered. A lack of good evidence for whether an intervention is successful or not is not the same as evidence for its ineffectiveness, as often the problems are methodological (with the design of the study) rather than associated with the logic or acceptability of what was offered to the carer. The characteristics of the research participants (carers and care recipients) are generally poorly described and very few studies appear to consider the fit between carers' stated or assessed needs and the model of service provided (the notable exception being those interventions that included a comprehensive assessment).

Consequently, results from evaluative research and systematic reviews of the literature on existing programs to support carers in their role (educational interventions, respite services, support groups) have not been very conclusive. The services offered do not seem to have an impact on carer burden; i.e., the interventions are not therapeutic in the sense of reducing a carer's score on a burden scale in the short term, but may be preventive or protective in the sense that a carer might feel better although no less burdened, or more capable of staying in the same caring situation for longer. A number of reasons have been outlined to explain this:

- (a) the outcome measures used have not been sufficiently sensitive to change;
- (b) the elements of the interventions have not been specific enough to meet carer needs; and
- (c) as interventions have, for the most part, been multidimensional, the type of evaluation performed has not been conducive to determining which components of the intervention were more or less effective. (Ducharme 2006)

The results in evaluations of carer support reflect these limitations. The goals of an intervention may not be made explicit enough. Is it mainly geared to benefit the carer or the care recipient or both? Is it expected to achieve something in the short term, or are longer term impacts more likely? Is it a 'therapeutic' intervention intended as a remedy to an immediate problem, like training on better management of a person's problem behaviours, or help in getting equipment for lifting or bathing, or assistance with medication management? Is it more 'protective' in the longer term, for example to increase the carer's capacity and resilience, sense of self-worth, or their access to resources, information, income from government benefits or part-time employment?

Interventions whose content can be closely specified are more likely to be shown to be effective. So helping carers with problem solving and cognitive restructuring produces measurable effects.

Interventions based on an individual approach are more likely to have significant effects (improvements in carer well-being) than those based on group approaches, because the former are better targeted and more intense. To date, few individual intervention models have been the focus of evaluative studies.

Taking into account the limitations of research to date as described in the body of the report, the key findings across the literature are:

### **Information giving**

Giving information alone (whether verbal or written) is not effective.

### **Case management and care coordination**

Although there have only been a small number of studies investigating case management and care coordination and the impact on the carer, the available evidence is promising.

### **Counselling and psychosocial interventions**

The overall evidence on counselling and psychosocial interventions is positive. However, some studies and reviews report no measurable effects.

There is little evidence on the effectiveness of different types of counselling or on dose effects. Likewise, the evidence on the effectiveness of counselling and other psychosocial interventions for different types of carers (spouses, parents, children, resident, non-resident, employed, young, old etc) is not strong.

### **Respite care**

The overall evidence on respite care is that it can provide small benefits. However, some studies and reviews report no measurable effects. The discrepancy between experience and evidence around the efficacy of respite care has been discussed in the academic literature in dementia. (Brodaty and Gresham 1992):

*“Recent momentum for increased provision ... is not supported by empirical data. Yet the literature is replete with anecdotal reports indicating the efficacy of residential respite. This discrepancy may have resulted from methodological flaws in the research, lack of awareness by consumers and health professionals and great diversity in the reasons for, and among the recipients of, respite. The prescription of respite care will need to be more specific and rigorous - matching the correct dose of respite care to the needs of recipients and caregivers - for future research to demonstrate its efficacy.”*

There is still little evidence on the effectiveness of different types of respite care or on dose effects. Likewise, the evidence on the effectiveness of respite for different types of carers (spouses, parents, children, resident, non-resident, employed, young, old etc) is not strong.

### **Educational and psycho-educational interventions**

The overall evidence on educational and psycho-educational interventions is good, especially for carers of people with dementia, mental illness and disability.

### **Family support interventions**

Reviews of family support services for patients with a mental illness conclude that family support interventions are effective. The evidence from studies of family support interventions is promising,

with four dementia studies concluding that it is a well-supported intervention and a randomised controlled trial of grief therapy in palliative care indicating effectiveness depending on the timing and careful selection of families based on their emotional characteristics.

As with most other interventions, there is little evidence on the effectiveness of different types of family support services, on dose effects or on the effectiveness of family support for different types of carers.

## Support groups

The number of well designed studies of support groups is limited, so the evidence on support groups at this stage is not established but is emerging. Having something in common is an obvious fact and there is emerging evidence that support groups may be appropriate for carers of CALD backgrounds, carers of children with disabilities and carers of people with mental illness.

## Multi-component interventions

Overall, there is good evidence for multi-component interventions, well summarised by the findings of one key review (Sörensen et al. 2002):

*Taken together, all caregiver interventions produced a significant improvement in caregiver burden, depression, subjective well-being, satisfaction, ability/knowledge and care receiver competence. Psycho-education and psychotherapy had a significant effect on all outcome variables. Multi-component interventions had significant effects on burden, well-being and knowledge. Respite was effective for reducing burden and depression and enhancing well-being. Individual interventions had stronger effects on burden and wellbeing, while group-based interventions had larger effects on care receiver competence. People caring for a dementia patient were less likely than others to benefit from interventions. Studies with a higher proportion of spouse caregivers (vis-a-vis adult children) tended to find smaller improvements in burden, depression etc, but greater improvements for care receiver symptoms.*

## The effectiveness of interventions for specific types of carers and specific types of care recipients

There is little evidence that the needs of carers systematically vary based on the type of person they are caring for. For example, there is little evidence to suggest that the needs of carers of people with dementia are different to the needs of carers of people after stroke. In both cases, the specific needs of the care recipient and attributes such as challenging behaviours do have an impact on the carer.

Interventions with carers of people with dementia have been the subject of the most research and, not surprisingly, the evidence is therefore strongest for this group.

Kissane et al. (2006) reported on a randomised controlled trial using 257 families of patients dying from cancer (including a sample in Melbourne) who were assigned to family focused grief therapy or a control condition. The authors concluded (p.1208)

*“Family focused grief therapy has the potential to prevent pathological grief. Benefit is clear for intermediate and sullen families. Care is needed to avoid increasing conflict in hostile families.”*

Research into effective interventions for carers of the ‘frail aged’ is surprisingly sparse. For example, we could find no intervention papers on ‘co-dependent’ carers (e.g., elderly couples who are each others carer and care recipient).

While there is some survey data on employed carers, no studies were found that specifically addressed how best to address their needs. Nor is there much evidence on the impact of different payment arrangements for carer support services (e.g., free, co-payments, vouchers).

There is also little evidence on what interventions are most effective for carers in different types of relationships with the care recipient - parents, spouses, children, friends, resident and non resident carers. However, there is evidence to suggest that the same interventions achieve different outcomes for different carers. For example, Sörenson et al. 2002 found that spousal carers benefit less than adult children and that carers of people with dementia benefit less than other carers.

There is some evidence regarding the impact of gender differences in carers. Pinquart and Sörenson (2006) conducted a meta-analysis of 229 studies published between 1983 and 2005, and looked at the significance of gender differences in carer stressors, social resources, psychological health, and physical health. They concluded that 'caregiving increases gender differences in depression and physical health, primarily because women experience more caregiving stressors' p.39, however, women and men did not differ in their use of informal and formal support.

Several studies have been reported on carer interventions for specific cultural groups. But no studies were found comparing the needs of carers from different cultures or the effectiveness of interventions across different cultural groups.

Only one study was found that focused on indigenous carers (McGrath et al. 2006). This was a study of the need for carer services for palliative care patients, rather than the effectiveness of such services. Lack of local respite services was documented to be negatively impacting upon the ability of carers to fulfil their caring duties and was found placing undue physical, emotional and economic stress upon carers, patients and their families. Lack of access to local respite services was found to be forcing rural and regional patients to relocate to metropolitan areas away from family, community and land to which strong ties are held. The authors reported that lack of respite services was found to obstruct patients' and carers' wishes for death to occur in their local community setting.

### ***Effective caring – implications for service provision***

The review of what we currently understand about carers' needs, and the most effective means of addressing those needs, points clearly to a much more directed and carefully planned area for service development and to how research can add value to service provision. Building a stronger and more generalised research culture in the carer support sector is the obvious backdrop that is needed, against which a series of specific strategies might stand out. These would be improving access to small grants so that services can evaluate themselves, encouraging the use of common tools for evaluation so that a lot of small scale activity might add up to something more substantial and providing a useful platform (or a clearinghouse) so that local lessons can be easily and practically shared with others.

Strategies for service improvement have a strong (but still highly variable) base of evidence that could be promoted as a platform on which to build:

1. There is a reasonable evidence base for the two main services currently provided (respite and counselling)
  - Although there is not much evidence (at the macro level) about the specifics (e.g. type, dose etc)
  - The useful lessons for the field are in the details in the tables in Volume Two.
2. There is reasonable evidence base on other interventions not usually funded/provided, eg:
  - Education / psycho-education
    - Especially for carers of people with dementia, disability and mental illness
  - Support groups

- The overall evidence is promising and there is emerging evidence of new support models. For example, support groups via telephone and video conferencing show promise as a strategy to support rural and remote carers
  - The evidence on support groups is sufficient to justify carefully evaluated pilots
- 3. There is a need to be clear about the goal of intervention:
  - Therapeutic versus prevention/protection goals
    - This requires good initial assessment and periodic reassessment
    - Supports investment in specifically-designed carer assessment
- 4. There is limited information in the literature about how to support young (adolescent) carers,
- 5. There is a clearer picture emerging from longitudinal studies on ‘transitions’ into and out of the carer role that indicates what can help to strengthen the capacities of the growing number of employed carers, many of whom are not linked into the service system
  - This picture includes getting information to people who may not identify themselves as carers, more flexible respite and service arrangements, removing workplace disincentives, potentially an increased role for payments and vouchers and research on how they can be better integrated with service-driven solutions.

### ***Effective caring – implications for research***

The carer research literature contains multiple recommendations for well-designed randomised controlled trials and there is no doubt that these are required to strengthen the evidence base for carer interventions. That said, the methodological challenges in conducting better (and more powerful) studies should not be under-estimated.

Despite these challenges, there is a strong case to promote and support more rigorous studies through the peer-reviewed grant processes of the NHMRC, ARC and other research funding bodies, so long as these are relevant to the priorities in the field of carer support. In the process, the research implications of studies to date (see Attachments 2 – 5) need to be considered.

Evaluations of current practice, if well designed, have the potential to fill the key gaps that currently exist in the literature, specifically in evaluating different models of care and payment arrangements (including dose effects) and the effectiveness of different interventions for different types of carers.

There is also a need to systematically collect better assessment and re-assessment data on carers accessing carer support services and to use that information to both routinely measure carer outcomes and to benchmark carer support services. Existing clinical outcomes and benchmarking centres (eg, the Australasian Rehabilitation Outcomes Centre, the Palliative Care Outcomes Collaboration and the Australian Mental Health Outcomes and Casemix Network) provide useful examples of such models.

Finally, the research agenda must include the capacity to identify the current and future un-met and under-met needs of carers. On all of the available evidence, the number of Australian carers will increase, as will the competing demands on them. Identifying the needs of Australian carers, and producing and using the best available evidence to meet their needs, is a national priority and there is a role for the research community in building that priority into health and social policy. That in turn might strengthen a ‘virtuous circle’ where effective services, based on better evidence, with communication of the findings, leads to better policy to support even more effective services.

## **PART ONE INTRODUCTION, BACKGROUND AND METHODS**

### **1 Introduction**

The “Effective Caring” project aims to identify the needs of carers, what helps to sustain them in their caring role and to develop and set out a prioritised research agenda in this area. The original brief requested a report that addresses four broad and inter-related areas of the academic and practice literature:

1. Support for carers
2. Importance of carer and family values
3. Factors affecting carers
4. Carer burden

The project has several stages:

- An international literature review (this draft final report)
- A workshop of key service delivery and academic experts aiming to identify:
  1. Priorities for improving routine practice in carer support networks
  2. Priorities for building a coherent research and development agenda
- A final report that incorporates both the literature review and the outcomes of the workshop.

This report addresses what has been gathered through a review of Australian and international academic and practice literature, and a concurrent analysis of policy and practice in Australia. The findings are designed to provide an evidence base, both for carer interventions and for a research agenda that complements and extends the work already done on assessing carers’ needs.

It is presented in two volumes. Volume One is this report. Volume Two contains the attachments.

### **2 Background**

In recognition of the difficulties experienced by people who provide care at home to dependent family members and friends, the Australian Government has greatly increased the level of assistance available to carers. For example, funding for the National Respite for Carers Program has been increased from \$19 million in 1996-97 to an estimated \$185 million in 2007-08. This additional funding has enabled the expansion of services to assist carers, particularly those that help them to obtain respite.

Assistance in obtaining respite is available through the Commonwealth Respite and Carelink Centres which provide free and confidential information on community aged care, disability services and other support services that are available. The Centres have recently received funding through Family, Communities and Indigenous Affairs for the Mental Health Respite Program. This program aims to increase access to flexible respite care options for carers of people with a mental illness/disability.

The NRCP also funds professional counselling through the National Carer Counselling Program delivered through Carers Australia and the eight state and territory Carer Associations, and specialist information and advice. These can be reached on the free call number 1800 242 636.

The 2005-06 Budget provided an additional \$207.6 million over four years for respite assistance. Of this:

- \$95.5 million over four years has been provided for additional respite services to support carers of frail older people who are combining caring and employment responsibilities or wanting to re-enter the workforce
- \$61 million over four years under the NRCP to provide overnight respite in home-like community settings for carers of frail older people
- \$41.8 million over four years to provide incentives for aged care facilities to increase the availability of residential respite for people with high care needs.
- \$93.3 million over four years in flexible funding to increase respite to carers in rural areas through Multipurpose Services.

Under the \$1.7 billion *Securing the Future of Aged Care for Australians* package, announced in February 2007, the Australian Government committed an additional \$26.5 million to the National Respite for Carers Program (NRCP) to fund the delivery of an extra 100,000 days of community-based respite to the carers of frail older Australians with high care needs. In addition, \$35.4 million over 4 years has been provided to establish Demonstration Sites for day respite in residential aged care facilities.

The importance of supporting carers in their roles is recognised in government policy at all levels. This is reviewed in Section 5 below.

The rationale for the current project was the need to assemble and assess the quality of the evidence behind interventions to support carers, such as respite care, and to identify best practice models, as well as identifying the particular types of services that may benefit specific sub-groups of carers. This information is then expected to inform a research agenda.

In 2006, CHSD undertook the development and field testing of a Carer Eligibility and Needs Assessment (CENA) tool, which was based on current evidence of best practice in the assessment of the needs of carers. It defined the construct of 'need' in terms of a number of domains that are relevant to the questions in the current review:

- Caring context
- Knowledge
- Functional level of care
- Care tasks and skills
- Health
- Social support
- Financial, legal and employment
- Coping strategies
- Confidence and competence
- Values and preferences
- Positive aspects of caring
- Strengths and risks

These concepts were translated into a series of questions (standardised data items) and related prompts and triggers for further assessment and referral for use in routine assessment practice in the community care sector (Ramsay et al. 2007).

This work followed and built on previous studies by the CHSD that involved reviewing and redesigning a set of needs assessment items, including carer profiles, for routine use by community health and community care services.

The development of community health information systems including carer profiles has progressed to a point where common information can be more readily shared, but is still well short of a common system. Development is best seen as a measure of standardisation being introduced over time for the purposes of program reporting, performance management and other efficiency objectives such as reducing multiple assessments. Combining items routinely collected in the range of 'minimum data sets' and performance indicators and other surveys, can add up to a system that helps to manage need, demand and supply.

The items combined into the CENA were field tested in three jurisdictions and used standard data items as well as revised and new items to characterise the needs, risks and strengths of carers. Some items were based on carer need studies including the Victorian Review of Respite Care Services Provided in the Community (Rowe et al. 1996), and the South Australian Carer Needs Assessment Trial (Maddock et al. 1998).

The CENA field-test and earlier work on carer profiles provided essential background information about, and clarification of, carers' needs and how they can be measured (Ramsay et al. 2007).

The effective caring project takes the next logical step beyond capturing indicators of need and risk, and reviews the evidence available to support the decision making about the service or information response. Once a description of the carer and care recipient characteristics and the levels of need and risk are assessed, that should give useful information that prompts a response. The aim of the project is to review and identify evidence so that interventions, along with information, can be used in the best way to assist in targeting services to those who will benefit most from them. Assigning the priorities to be followed among the sub-groups of carers that are identified through a review (employed carers, carers of people with dementia, young people as carers, older carers of offspring with a disability, etc) is a matter for a range of programs and policies.

## **2.1 Scope of the project**

The four key questions of the review can be broken down further into the following issues, which the project has addressed:

1. Who are carers in Australia?
2. What factors affect carers' ability to continue caring?
3. What is the evidence on effective approaches to carer support?
4. How does current practice compare to the research evidence?

Issues 3 and 4 are the major focus of the review with issues 1 and 2 being useful as background material to set the scene and determine the priorities for the proposed research agenda.

## **2.2 Definition of carers**

In the information sheet on the National Respite for Carers Program (NRCP), a carer is defined as "a person who, through family relationship or friendship, looks after a frail older person or someone with a disability or chronic illness. Carers look after these people in the community or in their own homes" (DoHA, 2006).

The project reflected the NRCP definition of a carer as referring to someone who has assumed the primary caring role for at least six months, and is not paid for their services. Carers can include friends and neighbours as well as relatives of the care recipient. Older couples living together are

often 'co-dependent' carers; that is, each plays the role of both carer and care recipient, depending on their needs and circumstances at the time.

The key priority areas for the *Effective Caring* project were:

- Carers looking after frail aged persons (including co-dependent carers)
- Carers looking after people with dementia and challenging behaviours

Of secondary importance were:

- Parents of adults with physical or intellectual disabilities
- Carers looking after people with acquired brain injury
- Carers looking after people with degenerative illness (e.g., motor neurone disease)

Still in scope, but not a major focus of the project, were:

- Parents of children with disabilities – included if they are mentioned in a wider context in a source, but not a specific search topic for the review
- Carers for people with mental illness – there are some difficulties in drawing a borderline between particular disabilities (e.g., ADHD, autism) and mental illness. This group is included where it is clear there is a disability associated with the mental illness
- Young carers (under 18 years) – included only if they are the primary carer.

### **2.3 Effective outcomes for carers**

The issue of the effectiveness of interventions, and by implication their intended outcomes and how to measure them, is not straightforward. It assumes a degree of consensus on the goals of the various programs and interventions for carers that are in scope, whereas in community care there are a range of goals of care for carers, care recipients and both parties.

These goals for the care recipient range from prevention and early detection of problems, to the maintenance of independence or the restoration of function, to treatment or palliation, or delaying or preventing admission to institutional care, i.e., emergency departments, hospital beds or residential aged care facilities.

For the carer the goals range from providing information and practical assistance, increasing confidence, reducing strain and burden, to enhancing quality of life. And for the relationship between the two parties the goals may be to strengthen bonds, increase social participation, through to the sustainability of caring arrangements regardless of the care recipients' goal of care.

Once the goals of care are understood, the service response is then mediated through a multitude of service types and multiple strategies and interventions. The interventions can be delivered in a range of different types of settings, for groups of clients whose conditions, needs and risks are diverse, and whose main common feature is that they are 'living in the community'.

The main focus in reviewing the literature in this project is on outcomes for carers, rather than care recipients, although the two are logically and practically inter-twined. Studies use a variety of outcome measures of carer health and wellbeing, care recipient health, wellbeing and function, and constructs such as carer strain and burden. The diversity of goals of the Australian community care sector means that the outcome measures of interest are not only those aligned with institutional interests, either from the hospital bed looking outwards, or from residential care looking back in time to see the factors that delay placement.

Carer quality of life, the quality and sustainability of the care-giving relationship, participation in care planning and service delivery and relationships between formal and informal carers all become part of the effectiveness and outcomes equations.

With a view to looking forward in a developmental strategy both for services and for a research agenda, the focus taken in the review of effective caring is on understanding the full mix of useful outcome measures and understanding the issues of the effectiveness of interventions within a broader frame of reference. That means not just looking at the 'gold-plated evidence' but also taking into account emerging or promising practice, and trying to encompass the diversity and variability of community care. These are the inherent factors in community care that make it less amenable to strict experimentation and the relatively tight control of the variables of interest.

As an example of the approach we are taking, there may be negative consequences of *avoiding* admission to hospital or residential care if the community setting does not meet the care recipient's needs, or if the arrangements are making a negative impact on the carer in a way that limits their ability to continue in their role. Nevertheless, the indicators that are the most commonly used outcome measures in studies of the effectiveness of carer interventions will be primarily those that are institutionally defined. Where possible, we have also sought out studies reporting other types of outcomes that reflect the intrinsic value of caring to the individual carer and the community.

## 3 Methods

### 3.1 Academic literature search strategy

The starting point for the literature search was a core list of key articles and reports already assembled at CHSD as part of previous work (e.g., the CENA project). These were analysed to identify key words and controlled vocabulary terms (e.g., MeSH) for use in the electronic searches.

The electronic databases to be searched included the Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE and PsycINFO, along with libraries of systematic reviews (e.g., Cochrane Library, Centre for Reviews and Dissemination). This strategy ensured thorough coverage of the academic literature. In addition, routine community care practice literature was sought from the web sites of other health service research organisations, government departments, relevant non-government agencies that commission or conduct research, national libraries and commercial sites. This search strategy is based on the COSI model (Bidwell and Jensen, 2004) which ranks searches in terms of their expected yield or return for time spent. We involved a university librarian in designing and conducting the searches.

The relevant references and, where possible, abstracts were downloaded into EndNote bibliographic software. Following an initial skim reading of the abstracts, the lists were refined down to the most relevant literature, and each item coded into the question it addressed.

### 3.2 Consultations and non-academic literature searches

Recent developments and current approaches to carer support in Australia have been documented by seeking expert opinion from service providers and other stakeholders, as well as searching key stakeholder websites (government, service provider and peak agencies) both nationally and internationally – predominantly UK, Canada and US. These searches sought to summarise the national policy environment, major statistical and consultancy reports, as well as the practice literature which would not usually surface using traditional literature search strategies. This ‘colloquial evidence’ (CHSRF, 2006) provides an essential context for the scientific evidence, to guide the selection and implementation of effective interventions for Australian carers.

The starting point for this part of the review was a number of reports and a body of practice literature collected by CHSD as part of previous work for DoHA and State/Territory jurisdictions. We undertook searches of key stakeholder websites, including looking at service and/or program reviews and evaluations, policy statements and other contextual information about carers. We also contacted (by telephone) service providers and peak body representatives who could provide guidance on useful documentation on the needs of carers such as local surveys. This work took place concurrently with the literature review and was not conducted as a formal survey. It was used as a means of discovering otherwise less accessible material by using advice from carer networks.

From discussions with key informants in the non-government and carer support sector, it appears that a ‘benchmark’ in terms of carer information internationally is the Carers UK website (<http://www.carersuk.org/Home>), which includes research reports containing evidence of carers’ experiences, statistics and policy recommendations, and a number of practical reports by the Centre for Social Inclusion at Sheffield Hallam University that could serve as a model for ‘packaging’ evidence on best practice (e.g. Stiell et al, 2006). This site was particularly useful, given the sheer size of the carer population in the UK (estimated to be six million), the level of sophistication of the Carers UK organisation, and the parallels in terms of the policy and service delivery context for Australian carers.

Searches of Australian State and Territory government websites revealed that the majority had initiated policy frameworks, action plans and/or legislation which recognises the role of carers and provides the foundation for their programs, services and policy responses.

### 3.3 Scheme for evaluating the evidence

The task for this project is to identify (1) carer needs and (2) interventions that have been subjected to rigorous testing and are both effective and relevant in the Australian context. The literature search for intervention studies has focused on those studies conducted in Western countries with similarities to the Australian population and/or health system.

The focus is on including the best available evidence. In relation to interventions, the starting point has been systematic reviews of randomised controlled trials. Where sufficient information was not available from these 'gold standard' sources, high-quality individual studies were sought. While the inclusion criteria gave preference to controlled studies published in the peer-reviewed academic literature, the search was not restricted to the academic literature. Instead, the review has accessed a wide range of data sources including the practice literature, surveys and policy documents.

The strength of the evidence has been summarised through the use of the classification system shown in Figure 1. The first five levels are hierarchical and relate to the strength of the evidence on interventions. The last five have been used to summarise evidence on carer needs. The evidence on carer views is used in the literature both as ways to understand carer needs and as an outcome measure in some intervention studies.

**Figure 1 Schema for summarising the strength of the evidence**

1. **Well-supported practice** – evaluated with a prospective randomised controlled trial
2. **Supported practice** – evaluated with a control group and reported in a peer-reviewed publication
3. **Promising practice** – evaluated with a comparison group
4. **Acceptable practice** – evaluated with an independent assessment of outcomes, but no comparison group (e.g., pre- and post-testing, post-testing only, or qualitative methods) or historical comparison group (e.g., normative data)
5. **Emerging practice** – evaluated without an independent assessment of outcomes (e.g., formative evaluation, service evaluation conducted by host organisation)
6. **Profiles** of carer population (e.g., routine data)
7. **Eligibility for support** (e.g., legislation, policy)
8. **Carers' views** (e.g., surveys, interviews)
9. **Expert opinion** (e.g., peak bodies, government policy)
10. **Economic evaluation** (including service utilisation studies)

This classification has been used to summarise each paper reviewed. In addition, the review of intervention studies has captured information on the following indicators of quality:

- Replication – has the intervention been implemented and independently evaluated at more than one site?
- Documentation – are the content and methods of the intervention well documented (e.g., provider training courses and user manuals) to control quality of service delivery?

- Theoretical basis – is the intervention based upon a well accepted theory or developed from a continuing body of work in its field?
- Cost-effectiveness – are cost-effectiveness studies available?
- Cultural reach – has the program been trialled with people in disadvantaged communities, Indigenous people and/or people from culturally and linguistically diverse backgrounds?

This system of evaluating and summarising the evidence for interventions was designed at the CHSD and is based on hierarchies originally developed by other organisations, including the Cochrane Collaboration, Campbell Collaboration (Shadish and Myers, 2004) and the California Evidence-based Clearinghouse for Child Welfare (CEBC): [www.cachildwelfareclearinghouse.org/](http://www.cachildwelfareclearinghouse.org/) , downloaded 7/9/06).

The difficulties of trying to apply Cochrane-style criteria for high quality evidence in fields outside medicine have been widely acknowledged. In its document on developing clinical practice guidelines, the National Health and Medical Research Council of Australia (NHMRC, 1999) states that “recommendations ... should be based on the best possible evidence of the link between the intervention and the clinical outcomes of interest” (NHMRC, 1999). This requirement is equally important in the field of social and educational interventions, where the goals of providing maximum benefit with minimum harm and acceptable cost also apply.

It is also acknowledged that the ‘highest’ level of evidence, i.e., systematic reviews of randomised controlled trials (RCTs), are not attainable in public health and social science evaluations of interventions, and that these important fields “should not be disadvantaged by the rigid application of a ‘hierarchy’ of evidence” (NHMRC, 1999, p. 14).

The classification system used for this literature review therefore represents a compromise. A Cochrane-style evaluation framework, classifying studies into levels of evidence based purely on study design, would not work well for this project. It would exclude many relevant studies, and would not provide sufficient information to judge the relative value of different types of studies. It was necessary to broaden the criteria and provide other details relevant to quality. This is because the project is not strictly speaking a systematic review (as defined by the Cochrane model); it is more a synthesis of the available knowledge derived from both high-quality research and consultation with experts in the field.

## 4 Results of the search strategies

### 4.1 Summary of the search strategy in the review of current practice

We used previous research on the carers sector for earlier projects and a search of websites and the results of the data base searches, plus contacts with key informants in carer associations and academic research groups and Departmental advice to identify policy and practice documents for review. Participants at the national workshop provided details of 20 additional key studies and reports that have been subsequently incorporated into this final report.

### 4.2 Summary of the database searches on needs and interventions

Three searches of the academic literature were conducted. The first two used a detailed literature search strategy documented in a recent review of the scientific literature into the effectiveness of respite care for frail older people (Mason, Weatherly, Spilsbury, Arksey, Golder, Adamson et al., 2007, 2007a). This review, which was published in the Health Technology Assessment journal, provided a guide to best practice in searching the topic of carers and caring. The concept of informal caring was carefully defined. Search 1 used this definition of caring, linking it with additional terms used by the authors of that review to narrow and focus the search results. This search strategy was run in four bibliographic databases:

- Medline
- Cinahl
- Psychinfo
- Cochrane Database of Systematic Reviews

The results were checked to ensure that the major known systematic reviews had been captured. In order to be sure that all the relevant carer literature was included, the search was run again in the same databases, using just the definition of carers and caring alone, without additional terms to narrow the search. Results from both searches were downloaded into EndNote and combined into one database (deleting duplicates) with a total of approximately 2000 references.

The third search strategy aimed to provide additional coverage of Australian literature not indexed in the major bibliographic databases. Meditext is an Australian bibliographic database that contains both academic and policy-related 'grey' literature. It does not offer sophisticated search facilities, so a simple title search was conducted using the term 'care\$'. This term captures any title with the word 'care' included. This produced 119 references.

One team member then read through all the abstracts and culled the references to reduce them to a manageable list of the most relevant papers. This process was checked by a second team member at the level of the abstracts.

The combined, culled database from the first two searches contained approximately 800 references. These were searched for the word 'intervention' in any field, resulting in a database of 295 references. One team member read a printed version of all the abstracts, selected those that were relevant to the study and assigned key words. A second team member then read the abstracts, adding key words and useful papers where relevant, and made the necessary changes to the EndNote database. The resulting database of intervention studies contained 110 references and this could then be searched on key words for the purpose of conducting the subsequent analyses. A further 99 papers were also included that focused on the needs of carers. An additional 21 papers and reports, models for understanding carer needs, examples of large scale surveys of carer needs were incorporated into the report as a result of the National workshop.

### **4.3 Reason for care and types of interventions**

Of these culled core references, 57 were review papers, including 51 'systematic reviews'. At the highest level of generality, the keywords were used to classify the reviews and studies in terms of the care recipients' conditions (their reason for care) and also in terms of the types of interventions that were used. This indicates that the largest body of evidence of effective interventions is for people with dementia, and that the most investigation is about educational or psycho-educational interventions, followed by psychosocial interventions and respite care. All but one of the reviews of effectiveness of interventions was able to be classified according to care recipients' reasons for care. This paper was, however, included in the classification of types of interventions.

Additional papers from sources other than the database searches (e.g., website searches, journal searches) were added to the EndNote database of intervention studies, with key words assigned by a team member who had read the abstracts. At this stage the database of intervention studies stands at 117 references.

### **4.4 Stress and burden**

The EndNote database containing results from searches 1 and 2 was also searched for the words 'stress OR burden' in any field, in order to capture papers that describe carers' needs and relationships between the characteristics of carers, circumstances of care and their perceived stress or burden. This resulted in a database of 165 references. Again, one team member read a printed version of all the abstracts, selected those that were most relevant to the study and assigned key words. A second team member then read the abstracts, adding key words and useful papers where relevant, and made the necessary changes to the EndNote database. The resulting database of studies on carer needs was then supplemented with additional studies from other sources as described above.

Within the 'carer burden' database, 11 papers address positive aspects of caring. Eleven present data patterns of service use for different types of care recipients or carers or changes in service use over time, two outline specific models of care, and five directly address carer support policies.

### **4.5 Types of carers**

In addition, it is possible to search both databases on key words that identify different groups of carers and whether the papers described their needs and/or types of interventions. The search of the Meditext database yielded 119 references. These were reduced to 90 by removing papers that focused on areas not directly relevant to the review, namely:

- Carer participation in service delivery
- Post-operative caring and rehabilitation
- Relationships between formal and informal carers
- Descriptive and service use studies
- Research methods for use with different groups of carers
- Professional or formal carers
- Carers for people with drug and alcohol problems.

### **4.6 Australian relevance**

In the final stage of the search strategy, two additional searches were conducted, using a search strategy developed by a university librarian. This strategy was designed to capture papers using Australian language and idiom. Search terms were derived from the glossary provided on the Department of Health and Ageing website, as well as terms used in the work plan for this project. The librarian-designed search was designed to provide broader coverage of different reasons for care, including disability, mental illness, chronic and degenerative conditions and palliative care.

## **PART TWO RESULTS – SYNTHESIS OF THE EVIDENCE**

As background information, and to put the evidence about effective interventions into context, this section on the review findings begins by looking at what is already known about Australia's carers and the factors that guide the responses to their needs. The policy and legislative context is covered in Section 5 and is characterised as evolving rapidly, and becoming more nationally consistent, from a period when carers were an under-valued adjunct to the primary aim of service provision, towards an explicit focus on carers' own needs and "the promotion of care as a foundational principle of citizenship and social solidarity." (Fine 2007, p. 225)

Section 6, on carers in Australia, covers a summary of what we know about carers, their numbers, types and a range of their characteristics from surveys of the general population by the Australian Bureau of Statistics and analyses by the Australian Institute of Health and Welfare. This section includes what we know about carer needs and strengths and the factors that affect carers' abilities to continue their caring role. The search strategy included evidence from large scale and longitudinal population samples, with work carried out by social research groups, as well as surveys of carers done by advocacy and research bodies.

Section 7 covers what we know about carers who are currently seeking respite and other community care services, on the assumption that these are a subset of the carer population who are identified by themselves or others as being able to benefit from some form of intervention. This group is characterised using information from the Carer Eligibility and Needs Assessment (CENA) data collection. That information is presented in the form of a profile of carers, as captured by a range of agencies in the 2006 national field trial, and illustrates two points: that as assessment comes prior to intervention, then the quality and scope of that assessment is important; and that information collected in routine practice can be useful for planning care, for understanding the need for community care, and for describing carer characteristics in local settings when screening-level information is aggregated.

Section 8 covers the key findings from the academic literature on the needs of carers, both in Australia and internationally.

Section 9 covers the key findings from the academic literature review on effective interventions. The format firstly looks at the evidence for the effectiveness of the types of services that are used by carers, the types of carers who use them and finally the types of care recipients who might benefit. The interventions examined are those most relevant to the national program: respite care, family support interventions, support groups, other specific interventions and multi-component interventions.

The final sub-section of Section 9 summarises the evidence on effective interventions across the specific types of carers (parents, spouses, children as carers, and evidence for the factors such as age, indigenous and employment status) and care recipients (frail aged, dementia, mental illness, stroke/brain injury, cancer/palliative patients, people with life long disabilities; people with chronic conditions).

## **5 The legislative and policy context**

### **5.1 Brief overview**

There has been a progressive inclusion of carers as a specific focus in legislation and policy at national and State and Territory levels since the mid-1980s. The Home and Community Care (HACC) Program was established by the Home and Community Care Act 1985 and brought together in one national agreement a number of programs previously administered as separate grants to the States and Territories.

HACC included the carers of frail older people and people with disabilities in its target group and was fully operational in 1986-7. In the first Triennial Review of HACC there was no explicit attention to carers as part of the target group. Informal carers were included as a principle of the Service Standards such that services should be provided 'in a way which recognises the role of the carer and their need for support and an independent and fulfilling life'. The amplification of the principle included that 'staff understand the role of informal carers' and 'involve them in decisions on the care plan where appropriate and include an assessment of their support needs.' (HACC Working Group, 1988, p.88)

The HACC program has been undergoing a continuous process of review and administrative reform since the time of its first review, in an effort to improve its integration with other similar programs and remove anomalies that disadvantage its target groups. The process of realignment and consolidation of programs was given specific attention under the National Health Strategy in 1991. It noted the recurring themes from numerous reviews, Senate Committees and Inquiries, Premiers' Conferences and working groups, of "overlap ... excessive administration ... leading to duplication of services or to significant gaps in services available ... (and) substantial problems" (National Health Strategy, 1991, page 11-12).

As well as the Home and Community Care Act 1985 there are two pieces of national legislation which are directly relevant to carers. The first is Part VB of the National Health Act 1953, which covered the Domiciliary Nursing Care Benefit (DNCB). The second is the Aged Care Act 1997 as it relates to residential respite care. The Aged Care Act 1997 relates to residential respite care and is still current. The Residential Respite Care Manual is an appendix to the Residential Care Manual (1999) and explains the residential respite care components of the Aged Care Act 1997.

Part VB of the National Health Act 1953 provided arrangements for the Domiciliary Nursing Care Benefit and was repealed in July 1999 under the Assistance for Carers Legislation Amendment Act 1999 (ACLAA). The Domiciliary Nursing Care Benefit (DNCB) was introduced in 1973 to provide some assistance to people who provided care for frail aged and other people with a disability who have been assessed as requiring nursing home level care. In 1999, the DNCB was incorporated into the Carer Allowance, which is administered by the Department of Family and Community Services and Indigenous Affairs (FACISIA) and delivered by Centrelink. The Carer Allowance combined the DNCB and the Child Disability Allowance and effectively broadened the eligibility criteria for receiving these benefits.

In 1996 the National Respite for Carers Program established Carer Respite Centres in each State and Territory. As the Program has evolved there have been additional targeted respite services from subsequent funding rounds. These have been targeted for specific functions such as carer support organisations, counselling services and shop fronts, as well as support for specific groups of carers such as those looking after people with dementia and working carers.

Within the broader community care policy context, essentially the same 'integration' aims that provided the rationale for the HACC Program in 1985 have been pursued in a range of administrative reform initiatives over two decades. The aims of reform have included improving efficiency and effectiveness, introducing service provision targets and performance indicators and making the 'system' simpler for consumers to use, while at the same time the number of separate community care programs continued to expand. As part of the reform strategy a number of reports were written to improve the ability to target service provision and improve outcomes (Fine and Thomson 1995).

In August 2004 the Australian Government released *A New Strategy for Community Care – The Way Forward*, outlining ways of simplifying and streamlining current arrangements for the administration and delivery of aged and community care services. The strategy aimed to make it easier for people to access the care that they need (Department of Health and Ageing 2004). As part of the community care reform agenda (in 2005), new tenders were let to consolidate carer-focused support services under the National Respite for Carers Program, the Carer Information Support Program and Commonwealth Carelink Program.

Another step towards more national consistency and common systems across programs was the development of common terminology and a set of shared assessment questions in the Carer Eligibility and Needs Assessment (CENA). The profile of carers, as shown in Section 7 below, illustrates what can be understood about carer characteristics and needs by using routinely collected data at the service delivery level (Ramsay et al. 2007).

In a related portfolio area the Carer Payment and Carer Allowance provide material support to help carers who are unable to support themselves through participation in the workforce because they are providing daily care for adults and children with a severe disability or medical condition. The Department of Families, Community Services and Indigenous Affairs (FACSA) is concerned about improving consistency between the different functions of government where carers have to negotiate with health and educational professionals about their caring role and substitute care, including in the mechanisms for assessing the care requirements of children and adults who have severe illness and/or disability. ([www.facsia.gov.au/carers](http://www.facsia.gov.au/carers))

A review of the Carer Payment (Child) was undertaken in 2007 and its documentation suggests there are opportunities for decreasing the complexity of the system for carers. Given their representation on the Reference Group, one outcome of the current project for this related portfolio might be as a source of advice on the use of a consistent base of evidence to guide eligibility assessment, decision-making and information-giving in both the community care service sector and Australian Government income support programs administered through Centrelink.

Table A9 (page 115) shows a brief overview of the development of the legislative and policy context that is relevant to carers from a national viewpoint.

## **5.2 Submissions to the Review of Subsidies and Services in Australian Government Funded Community Aged Care Programs**

The *Review of Subsidies and Services* was established in September 2006 to identify opportunities for a more integrated response to aged care that supports frail older Australians as their needs change. This work will complement that being undertaken through *The Way Forward*. Fifty-two organisations in total provided submissions, and comments and recommendations relevant to carer support programs were extracted from submissions sourced from the Department's website (accessed 23/07/07) and the key relevant recommendations are summarised in Table A10 (page 116).

In order to ensure that input from the sector was meaningful and of direct relevance to the issues under consideration as part of the Review, organisations, groups and individuals invited to make a submission were guided by a number of targeted questions. From our analysis of the submissions to the Review, they expressed a consistent viewpoint that emphasised the tendency of all jurisdictions to create new programs that meet specific needs but also lead to service gaps and overlaps. This was particularly around the HACC, CACP, EACH and Veterans Home Care programs, and with NRCP and residential respite, where in theory, each program aims to provide separate but complementary services, but the net effect can be confusing for the end users.

The submissions indicate that the issues around reducing complexity and improving community care integration remain a paramount concern, that the variation in the level and distribution of services provided under the various program types is significant and there is no obviously most efficient or effective way to reorganise the system and reform it to ensure that all types of clients will benefit. The most consistent messages from the submissions for the organisation of community care in general (including carer support services) were that at present clients can receive highly variable service responses and an amount of care that may not be commensurate with their levels of need.

The submissions to the *Review of Subsidies and Services* consistently noted that there is an overlap in respite services across other Australian Government programs and HACC, and that the

overlap with the Commonwealth State and Territory Disability Agreement (CSTDA) programs also needs to be considered, with the CSTDA providing respite and other support to people with a disability aged 65 and under.

### 5.2.1 Key points raised by submissions to Review of Subsidies and Services

*The Department of Families and Communities in South Australia* explicitly addressed the anomalies in respite care. “From an hour of in-home respite every few weeks to high care residential respite, for carers of frail older people and younger people with disabilities, the system appears to be much like a lottery as to who will receive how much of what and at what cost. Certainly there is evidence that carers of younger people with disabilities are increasingly accessing greater proportions of HACC and National Respite for Carers Program (NRCP) respite resources. Anecdotal evidence indicates that the ability of carers of younger people with disabilities to navigate the system and advocate for their needs exceeds that of the carers of older people, many of whom are older themselves, and who are more likely to have a culture of stoicism or gratitude for any assistance received than a rights or entitlement approach. This is likely to result in deterioration in physical health and capacity and increase risk of greater service need or institutionalisation.”

The South Australian submission pointed out that carer support and respite programs are worthy of comprehensive review in their own right, and recommended that:

- an integrated carer support and respite service be developed, taking account of all carer support and respite needs and services provided and that it sit alongside and closely aligned to the broader community care sector
- carer support and respite resources are strategically targeted and quarantined for the various target groups and this is determined on population and evidence based analysis to ensure transparency, equity and maximum benefit for funding allocated
- services provided are closely aligned to assessed carer needs and are in addition to identified carer community care needs and that carer needs are central to *how* respite is provided.

*Carers Australia* specifically addressed the National Respite for Carers Program, pointing out it “has achieved a great deal in terms of raising awareness of the needs of carers within general community care services. It has progressively developed protocols and procedures with other community care providers to govern work at the interface between services and minimise duplication in assessments for clients and carers.”

The work still to be done *within NRCP* was identified by the national carers’ body as:

- Better integration within the program and other community care programs
- Progressive increases in program funding to enable more carers to benefit from respite
- Coordinate the fragmented components of NRCP funding which are external to the Commonwealth Carer Respite and Carelink Centres, such as Commonwealth Respite for Carers funding, cottage respite funding and employed carers funding.
- There is a need to reduce the number of separately funded and targeted programs within NRCP.

The work still to be done *in other community care programs* was also identified in the Carers Australia submission:

- Protect the support services available to younger people with disabilities and their carers currently being delivered within the HACC program

- Ensure that sufficient funds are available to state and territory disability administrations to deliver care packages (usually required for longer periods) to younger people with disabilities and their carers
- Ageing carers of people with disabilities and ageing people with disabilities need to have a focus put on their specific requirements and have them addressed
- The need to provide support to both ageing carers and people with disabilities will challenge community care, as a consequence of issues at the interface between aged care, disability, mental health and health care services. Problem solving processes around the barriers that arise at the interface between services are required.

Carers Australia's submission pointed out that demographic change and an increasing preference of older people for care at home will occur at the same time as there are changes in the dependency ratio. Australian governments need to maximise workforce participation to sustain the economy. However, at the same time, there is a projected gap between the demand for and supply of unpaid family carers.

In addressing service needs into the future, governments will have to consider:

- incentives for intergenerational planning in advance
- incentives for sharing informal care within families to maximise workforce participation at least part time and reduce disadvantage
- supports and services required to maximise workforce participation including increased day care options for older people, and carer friendly workplace practices
- incentives and compensation for long-term carers of workforce age who are shut out of the workforce because of caring responsibilities (e.g. Government sponsored superannuation and workers compensation for long term carers).

The submission from *Queensland Health* addressed the role of Day Therapy Centres (DTCs), which are Australian Government funded and provide services of a restorative nature, such as physiotherapy, occupational therapy, speech therapy and podiatry. Unless clients happen to live close to DTCs, they are forced to access these allied health services from other community care programs, such as HACC, the Commonwealth State/Territory Disability Agreement (CSTDA) and the National Respite for Carers Program (NRCP) and have their nursing requirements serviced through HACC as they are not available through CACPs.

Queensland Health also addressed deficiencies and anomalies in respite. "Carer burnout is an ongoing problem when carers are only eligible to receive a community care subsidy for a maximum of 56 days respite care per financial year with a maximum of 28 days leave to use as social leave. This amount of respite is often insufficient ... (and) support should be available when the carer reaches a stage of 'not coping'. Therefore, respite services need to have capacity to provide emergency respite at times of crisis for the carer as well as providing regular, planned respite... It would be simpler if there was a single program for respite that offered the full range of service options, which could be delivered by a variety of respite care providers. This could include respite services currently delivered by HACC providers."

Queensland Health recommended that the Australian Government:

- Amalgamate the programs for respite such as the National Respite for Carers Program and respite through the HACC Program, into one program that offers a range of respite options that can be delivered by a variety of service providers operating at the local level.
- Recognise those programs which also provide respite to carers of people with a disability. Any amalgamation should ensure these carers are not disadvantaged.

- Education and Training for Carers to be able to access appropriate information, advice and support to enable them to sustain caring roles ... that have a preventive / restorative function and are not limited to tertiary interventions are required.

*Victorian Department of Human Services* also reinforced the theme of “overlaps and discontinuities when seen from the consumer’s point of view ...exacerbated by the present division of responsibility between the cost-shared HACC Program and the wholly Commonwealth-funded CACP, NRCP and EACH programs. In Victoria’s view, structural problems have led to a drift away from the policy intent of programs such as HACC and CACPs.”

The DHS submission pointed out the relative significance of State contributions in that “agencies delivering Commonwealth-only programs are a relatively small sub-set of the 488 agencies delivering HACC. Care packages (CACP and EACH) are delivered by 97 agencies and carer support (NRCP) by 49 agencies.”

“Reducing complexity for clients and carers by simplifying the system rather than requiring case management to navigate the complexities of the system... (and) refocusing services to apply a restorative approach in assessment and service delivery” was described as the preferred Victorian path to reform.

Victoria proposed that “residential respite care for older people should remain with the residential aged care program as a fully Commonwealth-funded program, and that access to residential respite should be coordinated through ACAS.” It also proposed the merging of the Day Therapy Centre program and NRCP into HACC Basic on the grounds that the services delivered, the client groups served and the participating agencies all align closely with HACC Basic rather than being focused on clients in the ‘package care’ tier.

“Victoria’s preferred option is for DTC funding to be folded into HACC Basic to allow for the coherent development of allied health services through HACC and state-funded health programs. This approach would also allow for negotiation with individual agencies to promote service delivery consistent with agency capabilities and roles in local and regional networks as well as a clearer focus on a restorative approach to service delivery... More providers should each be able to deliver a range of respite and carer support services, rather than different agencies providing different kinds of respite. Like HACC, NRCP funds all age groups. Victoria would also consider folding in relevant programs that it funds, to further strengthen basic care and simplify access.”

The submission from *Uniting Care Ageing NSW and ACT* pointed out the “main problem with the Basic Care Tier is its fragmentation, being funded and regulated under too many different programs and different government departments e.g. HACC, NRCP, VHC. We appreciate that this review is focused more on older Australians with complex care needs and their carers (Packaged Care Tier), but this fragmentation is an obvious, well-documented issue that contributes to program boundary problems both within and across all of the tiers in the system.”

*The Department of Health and Human Services Tasmania* reinforced the theme that program boundaries create inequities for clients and that the “variation in services provided under the various program types is so significant that clients ultimately receive an amount of care that can range from one to 50 hours per week.”

The review of the national legislative and policy context and the submissions to the Review of Subsidies and Services give a description of the range of national concerns in the carer support sector. How carer support issues have been addressed separately by the States and Territories is reviewed in Section 5.3, before the implications for service development and further research of this material on current practice are discussed in Section 5.4.

### 5.3 State and Territory initiatives in response to the needs of carers

The focus on carer policies and programs at State and Territory level is a relatively recent trend. Traditionally, the service focus has been on the provision of direct support for carers, in the shape of services such as respite, the provision of information and the provision of financial assistance in the form of carer allowances. Over the last decade, however, there has also been a shift toward the development of more indirect and 'enabling' policies and programs especially at State and Territory level.

Table A11 (page 118) describes the legislative context and policy frameworks that are currently relevant to carers in each State and Territory.

It is evident in the table of State and Territory initiatives that formal care and support services are now commonly understood as important adjuncts to a broader societal context which supports people in their caring role. In recognition of the impact that the broader society and a range of social programs have in facilitating and underpinning the traditional support programs, and the potential for enhancing the lives of carers, the States and Territories are now supporting a range of 'enabling' frameworks in legislation, action plans and specific carer support initiatives.

Enabling policies such as anti-discrimination legislation, community awareness campaigns, and the various State and Territory Carer Action Plans/Frameworks aim to provide a more holistic community approach to supporting carers in the mainstream of service provision.

These changes reflect the role of Australian Government initiatives to support advocacy and policy development by carer organisations in the disability, mental health and elder/aged care sectors. Engaging with existing State and Territory programs, the focus is on broadening community engagement, social participation and equal opportunity rights.

A notable example of the impact of advocacy and networking in mental health comes from a report by Carers Australia (2006). It describes two years of work in mental health that included networking and policy development and a focus on the impact of changes to mental health legislation in the Northern Territory that included improved access to information and more formal rights and roles for carers. The national impact of this work was seen in NSW where the new Mental Health Act 2007 came into operation on November 16 and it now includes explicit roles for *primary carers* to be nominated by patients and for carers to be informed of civil commitment proceedings and to be included in the care plans of mental health facilities when making community treatment orders.

States and Territories have also enacted their own legislation to improve access and involvement in mainstream care provision for carers and provide adjuncts to care recipient and carer benefits and allowances. The focus on changing mainstream services is through Action Plans and Carers' Charters and by joint ventures and programs with affiliates of Carers Australia. There are examples in all States and Territories of joint programs with a specific carer focus in aged care, disability and mental health.

Two initiatives emerging from the Queensland Carer Action Plan (in May 2007) are the introduction of a Carer Card (for those who receive the Centrelink Carer Payment and/or Carer Allowance) and a Companion Card. The Carer Card provides discounts at participating businesses, similar to the existing Seniors Card and Foster Carer Card. The Companion Card also exists in Tasmania and is for eligible people with a disability who are unable to participate at most community venues or activities without attendant care support and who will need this level of support lifelong, and allows free admission for their chosen companion at participating venues and activities.

## 5.4 Implications for service development and research

The national legislative and policy context shows a progressive growth of sophistication in the way that carers and their roles are understood, from marginal to policy formation to more central and from a generalised part of the 'integration problem' to being treated as a segment of the service population and as well being a resource for the client they are a focus of effort in the community care sector where their needs are to be understood in their own right.

The continuation of this trend appears inevitable, both in the focus on carer support interventions in the mainstream of service provision (implying a more consistent approach to carers across programs), and within the specific carer support programs (implying continued development and expansion of the NRCP and State and territory based carer support programs). Underpinning that likely growth with more coherent and effective intervention strategies appears to be an essential next step, as does a carefully prioritised and sequenced program of research and development.

Taken overall, and in the context of current practice in service provision, the submissions to the *Review of Subsidies and Services in Australian Government Funded Community Aged Care Programs* reinforced and specified the policy and practical limitations of the current systems that were described in the brief review of national legislation and policy. They offer no new evidence beyond that used as the rationale for the Community Care Review and *The Way Forward* agenda, but do give a valuable summary of current concerns in the States and Territories and as expressed by some of the larger provider agencies and Carers Australia.

The messages that stand out for the carer sector from the submissions on current issues are that the problems created by program boundaries and Commonwealth-State and Territory relationships are long-standing, intractable and frustrating in spite of the large amount of common ground. The challenge for carer-oriented programs is not to further compound fragmentation problems by integrating in one direction (for the benefit of carers) at the expense of separating out from the wider system of support.

From the review carried out for this project the States and Territories and advocacy groups point out there is clearly scope for work within the carer support sector, in merging the different types of respite under a common set of guidelines and a funding model that would encourage greater equity and consistency. The different eligibility criteria for the growing range of programs, entitlements and allowances at State and Territory and national level pose a continuing challenge for the ongoing theme of integration (Leutz, 2005), aimed at reducing complexity for the consumer/client/carer and improving integration across the range of human services.

Overall there is a call for a clearer division of labour and combined effort, a focus on restorative and rehabilitation strategies, and providing a common a base for training and support for carers and workers in the community care sector. The caveat about a common approach is that younger people with a disability and their carers may still require tailored programs so as not to be lost in demands from the much larger numbers of frail aged. That implies considerable development work (on information management and the use of common assessment and care planning systems) that is yet to be done inside the disability sector.

If improving the focus on carer support interventions is to avoid fragmentation and to mesh with the wider system reform agendas, then that implies a consistent approach (at the very least): between sub-programs within the NRCP; the systems of income support for carers; the disability sector; and State and Territory based carer support programs.

While there are gaps and inconsistencies, the overall variability in the approaches to carers' issues, the various Carers' Charters and the activities of the carer-related programs between the States and Territories are minimal. This is a testament to what has already been achieved over the past decade in building a national approach and to the degree of coherence that can be brought about by well-networked carer advocacy and support groups.

So there is still room for greater consistency and standardisation on a national basis that can move on from a base of there already being loosely federated similarities. This is not to achieve uniformity, or a lowest common denominator for its own sake, but so that carers might expect similar eligibility criteria, rights in service provision, entitlements to support and assistance in social participation, that are more uniform on a national basis in the future.

Policy analysis, research and development work in identifying a common set of points in a national Carers' Charter would be straightforward, as would the promotion of nationally consistent eligibility criteria for a range of support and entitlement programs. This would improve equity and access for carers across all jurisdictions.

The technical points made by the Australian Institute of Health and Welfare's submission to the Review of Subsidies and Services deserve highlighting in their own right. They are of particular relevance in considering the research and development agenda for carer programs, and more streamlined procedures for data access. Steps were proposed to reduce the gaps in the evidence base. "A linked national database base (suitably protected) derived from the linking of data from the Aged Care Assessment Program, Community Aged Care Packages and Extended Aged Care at Home, National Respite for Carers Program, Residential Aged Care program (including residential respite), and Home and Community Care would be of considerable benefit in addressing many of the questions posed by the Review."

## 6 Carers in Australia

This section covers a summary of the literature on what is known about carers in Australia from population surveys by the Australian Bureau of Statistics, reports by the Australian Institute of Health and Welfare, as well as studies of specific carer needs and support issues by research groups and advocacy bodies. It briefly reviews the available sources of evidence and documents the findings as a compilation and description of the carer population, their numbers, types and needs, and then relates that information to a summary of the international literature on carer needs and supports.

An alternative approach from the point of view of service entry points can be used to describe a profile of carers. This is used in Section 7 below where we address the question of ‘what do we know about carers seeking respite and other community care services?’ This profile is based on data from the recent field trial of the CENA assessment tool (Ramsay et al. 2007).

However, a research and development agenda and useful framework for building more effective practices in carer support do not come about by adding up the sum total of what is known about carers and their needs. The application of some organising principles and a measure of useful theory to guide the setting of priorities is also needed for such a diverse sector.

In a recent book on the theory, social policy and politics of the provision of care called *A Caring society? Care and the Dilemmas of Human Service in the 21<sup>st</sup> Century* (Fine 2007a), a framework including the “social division of care” was proposed to cover both formal and informal care issues and for guiding research through understanding the core social policy debates surrounding care. The debates that are described are concerned with “the demography of ageing societies ... (that) foretells a coming crisis in care.” Such a crisis cannot be “simply projected directly from raw population figures” but also includes issues such as the “work/life conflict” and the “substitutability” and “affordability” of sources of care, creating dilemmas that “are far greater than simply finding the cheapest alternative form of provision.” (p. 21)

This discussion of the dilemmas of care points to the value of engaging in a research and development enterprise that over time could go beyond just backing up a range of practical service interventions with evidence on their effectiveness. A “wealth of research exists that documents the importance of care. Nor is there a shortage of powerful and imaginative ways of theorizing the topic, with major contributions produced by feminists, moral philosophers, social policy analysts and other social scientists demonstrating the exciting potential that acknowledging care has for re-imagining social life in the twenty-first century.” (p. 222)

Moving from theory into a practical research agenda involves going beyond “a generalized, abstract concept of care ... and beyond general assertions about its importance. Careful analyses of the changing needs for care, and the problems faced by care-givers under different circumstances must continue to be undertaken. But a mountain of empirical data on its own is not enough.” (p.223). Michael Fine concludes his analysis of the dilemmas of care by highlighting the importance of what is being proposed in the current project, albeit with less of an emphasis here on the theoretical dilemmas. “One of the key tasks is to identify the gaps and silences ... in the policy and professional literature in order that they might be remedied.” (p. 225)

In a subsequent journal article for the Australian Council of Social Service Fine considers the task of creating a common agenda to “help create the dialogue and sharing of ideas that a more mature field of research and practice requires ... to provide a joint framework for data collection and for monitoring the changing balances of responsibility for providing care.” (Fine 2007b, p145) The following sections show that in these terms Australian research is well placed for understanding the availability and characteristics of informal carers, and in a strong position to develop a research agenda for the longer term task of creating a practical and equitable balance in the social division of care.

## 6.1 *The numbers of carers in the community*

There are reliable and routinely collected statistics in Australia on the numbers of self-identified carers based on the Australian Bureau of Statistics' (ABS) Survey of Disability, Ageing and Carers (SDAC). The Australian Institute of Health and Welfare (AIHW) has used the same data to present a picture of informal care to answer questions about primary carers, who they assist and what caring involves.

However, not all carers chose to identify themselves as such in surveys, with some seeing their role primarily as spouse, son, daughter, friend etc. This suggests there may be under-estimates of the number of carers in population surveys, and that there is also a cohort of 'hidden' or 'isolated' carers. Longitudinal survey data on the characteristics of women as carers in the community has been used to investigate "hidden carers" or those who do not necessarily identify themselves as carers, and data from the Australian Longitudinal Study on Women's Health (ALSWH) (Lucke et al. 2006) as described under Section 6.1.7 below has been analysed to provide information to support policy development for the Employed Carers Innovative Project (ECIP).

Data from the longitudinal study based on the Household, Income and Labour Dynamics in Australia (HILDA) Survey have been examined (Bittman et al. 2007) to investigate the effect of caring on employment, hours worked and earnings and this is described in Section 7.1 below. This type of data can also add to the body of useful information on the care tasks of people in the general population who do not necessarily identify themselves as carers.

The following sub-sections summarise the key points of what is known about carers in the community from a population survey sources. A multitude of smaller scale surveys on particular sub-groups of carers, selected either by the type of disability of the care recipient, or from surveys in particular localities, have been carried out by Carer Associations, academic researchers and disability groups.

### 6.1.1 *The Survey of Disability, Ageing and Carers (SDAC)*

The Survey of Disability, Ageing and Carers (SDAC) was conducted by the Australian Bureau of Statistics (ABS, 2004) throughout Australia, from June to November 2003 to collect information about three population groups:

- people with a disability
- older people (i.e. those aged 60 years and over)
- people who provide assistance to older people and people with disabilities.

"In 2003, there were 2.6 million carers who provided some assistance to those who needed help because of disability or age. About one fifth of these (19%) were primary carers, that is, people who provided the majority of the informal help needed by a person with a disability. Just over half (54%) of all carers were women. Women were also more likely (71%) to be primary carers. Of those providing care, 1.0 million (39%) were in the 35-54 year age range. This age group's caring responsibilities involved children, partners and/or ageing parents.

Those who provided care to people with a disability were more likely to be older and/or have a disability than those who did not provide care. Twenty-four per cent of primary carers were aged 65 years and over, compared to 13% of the total population. Of those living in households, the disability rates were 40% for primary carers, 35% for all carers and 20% for non-carers." (ABS, 2004)

About one in five carers were identified as primary carers who provided the majority of informal help to a person with a disability. Most primary carers (78%) cared for a person living in the same household. The 45-54 years age group contained the largest number of both male and female primary carers (32,200 and 83,400 respectively).

In 2003, the percentage of people living in households that were identified as carers increased gradually with age from 9% of 18-24 year olds to 22% of 55-64 year olds, and then declined to 18% of those aged 75 years and over, although this was 5 percentage points higher than the overall rate of 13%.

The proportion of people who were primary carers also increased gradually with age, from 1% of 18-24 year olds to 5% of 55-64 year olds. Unlike the overall carer rate though, it did not decrease for the older age groups, staying at 5%.

### **6.1.2 Detailed findings from analyses of population surveys**

Australian Bureau of Statistics (2003) presented results from the Survey of Disability, Ageing and Carers (SDAC) conducted from June to November 2003 (Disability, Ageing and Carers, Australia: Summary of Findings, Catalogue No. 4430.0). The final sample comprised 36,241 people for the household component and 5,145 people for the cared-accommodation component. The primary objective of the survey was to collect information about three population groups: people with a disability; older people (i.e. those aged 60 years and over); people who provide assistance to older people and people with disabilities.

The SDAC survey was a major achievement for the community care sector as much of these data have underpinned subsequent analyses of population need and provided the basis for negotiating agreements between jurisdictions on program allocations.

In their 2004 report, the Australian Institute of Health and Welfare (AIHW) present a picture of informal care in contemporary Australia (AIHW 2004) based on the SDAC data. The report sought answers to the following questions: who are the primary carers, who do they assist and what does caring involve? The report also explored the impact of caring work and patterns of formal service use with informal care. By revisiting the 1998 ABS data and other key studies, the AIHW report was able to explore some issues in more detail and report a more complex profile of carers in Australia. It has built on "a growing body of research that has identified the characteristics of carers and the extent of burden of their carer role." (p. 2)

The main findings from the AIHW 2004 report (pp xii-xvi) were described under a series of headings covering the characteristics of carers, the demands on them, the changing context, wider social trends and the relationship to formal services. These findings are outlined below followed by observations of their significance for community practice in carer support, or for a continuing research agenda.

#### **Who are the primary carers?**

Caring for a person with a severe or profound core activity restriction in a community setting is predominantly a female occupation. Men and women are more equally represented among carers of people with any level of disability than among primary carers of people with a severe or profound core activity restriction.

Over half of primary carers cited family responsibility as the reason for taking on the caring role; other common reasons given by primary carers were 'could provide better care' and 'emotional obligation'. A similar proportion of partner and parent carers said that they could offer the best possible care for their family member.

Overall, 79% of primary carers in 1998 lived with their care recipient; the rate of co-residency among primary carers of people aged 65 years or over is somewhat lower (62%).

## Demands and consequences of caring work

Primary carers had a lower labour force participation rate (39%) than people who were not carers (68%). 37% of primary carers spent on average 40 hours or more per week providing care and 18% spent 20 to 39 hours per week. Over one-half of primary carers spend 20 or more hours per week in the caring role and over one-third spend 40 or more hours per week on unpaid caring work.

Three-quarters of primary carers in 1998 had spent at least 5 years in the caring role and 40% had been caring for at least 10 years.

Detailed data collected by the ABS on co-resident primary carers in 1998 revealed that 60% of care recipients *always* needed assistance with between one and four activities of daily living and a further 24% *always* needed assistance with between five and nine activities of daily living. The intensity of a caring role is reflected in substantially lower labour force participation among working-age carers compared to non-carers of the same age, with an inverse relationship between primary carer labour force participation and weekly hours of caring work.

Negative consequences of a primary caring role reported by primary carers in 1998 include reduced hours of paid employment and resignation from positions of employment, lower overall life satisfaction and a reduced feeling of wellbeing, and increased feelings of fatigue and depression.

### Implications for policy and practice

Caring as a mainly female occupation has two implications, one being the need to strengthen older women's networks and improve the capacity of those networks to offer mutual support and practical assistance, and the second implication is the necessity to promote more gender equity in the caring sphere, with attention to promoting men's roles and abilities as carers.

Growing numbers of frail aged care recipients over the coming decades highlight the importance of training in manual handling procedures for carers and access to mobility and bathroom aids. This short list of practical tools can be extended to include the management of medicines, the growing number of home health monitoring tools, medical devices, and tele-health aids, as well as more permanent home modifications.

Beyond strengthening the capacities of carers to cope in the home environment there is also the need to develop social strategies for greater workplace assistance for employed carers and easier access to income support in reinforcing the value of the carer role.

### 6.1.3 Findings from analyses of other carer survey data in Australia

Prior to the 1998 ABS survey and the subsequent AIHW reports, the Victorian Carers' Program survey, reported in Schofield et al. (1997), was the most thorough description of family carers available. It was based on a state-wide random population survey of 26,000 households, carried out by telephone, from which the self-identified carers were selected. From that selection 78% (N= 976) were interviewed in more detail to create a socio-demographic profile that included the characteristics of care recipients and their difficult behaviours, as well as the carers' physical and emotional wellbeing, their need for assistance and use of informal and formal supports (p. 60).

In 2000 the Carers Association of Australia produced its report on the results of the 1999 National Survey of Carer Health and Wellbeing, called *Warning—caring is a health hazard* (Carers Association of Australia 2000). That report described the pressures experienced by carers, including the decline in their physical, mental or emotional health as a result of their caring responsibilities, with nearly 60% reporting major negative effects on their life choices including restrictions in their ability to take part in paid work, education or other career opportunities.

The Carers Association of Australia's Young Carers Research Project in 2001 (as reported in AIHW 2004) revealed that young carers experience similar negative effects, compounded by systemic lack of recognition of their existence and circumstances.

#### 6.1.4 Carer health and well-being survey 2007

Carers Australia contracted with Deakin University's *Australian Unity Well-being Index Project* to survey approximately 4000 carers, contacted through the data bases of the state/territory Carers Associations. The survey was used to assess factors concerning their personal well-being, depression and stress using standardised scales (in particular the Personal Well-being Index) and additional questions related to their carer situation (Cummins, Hughes and Tomynt et al. 2007). [http://www.deakin.edu.au/research/acqol/index\\_wellbeing/index.htm](http://www.deakin.edu.au/research/acqol/index_wellbeing/index.htm)

The report on the survey focussed on the subjective wellbeing of family carers in Australia. The Personal Wellbeing Index score is the average level of satisfaction across seven aspects of personal life (health, personal relationships, safety, standard of living, achieving in life, community connectedness, and future security), and two additional psychological outcome measures were used and these were the depression and stress sub-scales from the Depression, Anxiety and Stress Scale.

In summary, carers have the lowest collective wellbeing score of any group Deakin University has sampled, and have an average rating on the depression scale that is classified as moderate depression. Female carers have lower wellbeing than male carers, and the most disadvantaged carer household group is sole parents.

The report reinforced the known characteristics of the group of self-identified carers who are connected to Carer Associations. It presented the results under five headings.

- Demographics and Employment

The survey reinforces the usefulness of recent initiatives for those carers who are employed, as over one third of those surveyed has a degree of worry about losing their job that depresses their wellbeing even further.

- Carer Challenges

The wellbeing of carers is more vulnerable to physical pain than is normal, are more likely to be experiencing chronic pain, to be carrying an injury and/or a significant medical or psychological condition is associated with lower wellbeing. Carers are likely to be not receiving treatment for themselves for a significant medical or psychological condition as they have no time or cannot afford the treatment.

- Carer Resources

The wellbeing of carers is less than that of the general population sample and their satisfaction with their ability to afford the things they would like to have, and to save money are all severely comprised for carers compared with a general population sample.

- Intensity of the Carer Role

Wellbeing decreases linearly as the number of hours spent caring increases and primary carer responsibility for any time each day is extremely damaging to wellbeing. Female primary carers have lower wellbeing than male primary carers and caring for adults imposes fewer burdens than caring for disabled children. The wellbeing of the 3,049 people (83% of the sample) who live with the person requiring care is 58.4 points, the lowest value recorded for large samples.

- Satisfaction with Caring and Leisure.

High satisfaction with leisure is more strongly associated with higher carer wellbeing than satisfaction with caring hours.

### 6.1.5 Other investigations of need

The following sub-sections are specifically focussed on what we know from general population studies, in particular from cohorts followed over time. The emphasis is on carer roles and demands on their time, the factors that affect carers' abilities to continue their caring role and transitions in and out of caring responsibilities. It reviews evidence from large scale and longitudinal population samples, along with some of the current work being carried out by social research groups. The sub-sections also cover economic analyses and smaller scale studies and surveys of self-identified carers done by advocacy groups and research bodies.

### 6.1.6 Household, Income and Labour Dynamics in Australia

Michael Bittman and his colleagues have examined the effect of caring on employment, hours worked and earnings, and general outcome measures (self-rated health and life satisfaction) of carers as part of a broader project that aims to map the longer term effects on carers' life circumstances. The broader research project is supported by an ARC linkage grant in partnership with a consortium of relevant NSW government departments and Carers NSW (Bittman et al. 2007, p. 258, 270).

The project uses data from the longitudinal Household, Income and Labour Dynamics in Australia (HILDA) survey. The survey was initiated and funded by the Australian Government Department of Families, Community Services and Indigenous Affairs (FaCSIA) and managed by the Melbourne Institute of Applied Economic and Social Research. The HILDA survey began in 2001 and is following a multi-stage random national sample of 7,682 households (13,969 people).

HILDA data can add to the body of useful information on the care tasks of people who do not necessarily identify themselves as carers. The information produced is different to that collected in the ABS (SDAC) survey in that it provides more detailed information on hours worked, earnings from employment and income from other sources.

“There is no specific question identifying carers in the HILDA, as yet. Nevertheless, it is possible to identify carers of adults ... by using a mixture of responses to questions in the personal interview and ... self-completion questionnaire.” (p. 259) It is possible to draw inferences about how much time they spent caring for an adult and to classify their caring responsibilities.

The HILDA Wave 1 data on women (13%) and men (9%) reporting care responsibilities is roughly in line with the ABS estimate of 12.5% of the adult population, and the proportion reporting intensive care responsibilities stays stable across all waves – being relatively small at 3-4% of females and 2% of males. The ABS estimate is that primary carers represent 2.4% of the adult population.

Any caring may lead to exclusion from the labour market, and the loss of income is significant. “In the cross-sectional analysis, the intensity of caring is inversely related to the rate of full-time employment. As caring responsibility intensifies, the rate of full-time employment falls, until it is 3-5 times lower than those with no caring responsibilities ... only 10 to 15 per cent of carers who have intensive care responsibilities work full-time. This suggests that it is difficult to combine even a moderate amount of caring with full-time employment.” (p. 261)

“While the growth of informal care has shifted much of the cost of caring off the budgets of the federal and State governments, it has done so by transferring the cost to private households, and within these households, predominantly to women.” (p. 268) The impacts of caring on employment and income found in the HILDA survey are similar to those described for women in

the Australian Longitudinal Study of Women's Health (ALSWH) described below. Understanding those costs, specifically for women, is the subject of this separate longitudinal study, which is reviewed in the next sub-section.

### 6.1.7 Australian Longitudinal Study of Women's Health

The Australian Longitudinal Study of Women's Health (ALSWH) follows 40,000 women over 20 years in three cohorts (young, middle aged and old), surveyed every three years about their health and well being and social circumstances. The National Respite for Carers Program has commissioned research on the mid-age cohort examining the impact of caring responsibilities on paid employment based on the data from the fourth survey (Lucke et al. 2006), changes in caring roles between the third and fourth surveys (Berecki et al. 2007), and a pilot sub-study designed to improve questions for exploring the transition to caring, service use and the role of services to lessen the negative impact of caring on the lives of carers (Watson et al. 2007).

The focus of the commissioned research from the ALSWH group is on exploring the details of the caring responsibilities of women in mid life, through a population approach, using survey methods that do not rely on sampling women who have initially identified themselves as carers. The work aims to support policy development for the NRCP and in particular the Employed Carers Innovative Project (ECIP), a project implemented nationally within a range of sites with agencies funded through the NRCP.

The rationale that shaped the questions being asked of the ALSWH data and the pilot sub-study comes from the analyses by AIHW (described above) on the impact of social trends on the need for and availability of primary carers. Projections of high growth in the age groups from which large numbers of primary carers are traditionally sourced may be counteracted by the effect of a moderate reduction in the proportion of working-age women who are willing to reduce paid work to become care-givers.

The purpose of the commissioned research was to find useful information to improve service responses that may allow women in particular to balance work and life responsibilities. The data from the fourth survey on the mid-age cohort are useful to investigate the factors that are likely to influence decisions to care for family members or friends, to investigate the types of respite and support services that may help to maintain care-giving roles, and to examine the benefits of keeping carers both in the workforce and in their caring roles (Lucke et al. 2006, p.1).

Report 1 was based on Survey 4 and covered 10,905 women aged 53 to 58 years. It examined carers (live-in and living elsewhere) and non-carers, and constructed a 'Care Index' (combining frequency and amount of caring). There were three occupational groupings (71.7% were in the labour force: 36.1% part time; 35.1% full-time; and 27% were not in the labour force).

The Report examined the relationships between caring and employment, with live-in carers least likely to be employed, and part-time workers most likely to be caring for more than two people. Live-in carers found it most difficult to manage on their income. With lifestyle factors there were few differences between the carer groups, but non-carers reported higher levels of social support and live-in carers reported lower availability of support. It was not surprising that live-in carers feel more rushed and this related in the expected direction to their employment status.

In terms of health factors, the findings in Report 1 showed live-in carers had the poorest mental health scores and the lowest optimism scores, and the highest stress. They reported more physical symptoms, were more likely to have seen their GP and had the most sleep problems when compared with non-live-in carers and non-carers.

Report 2 from the ALSWH was on *Changes in Caring Roles and Employment in Mid-life* (Berecki et al. 2007) and presented findings related to 'transitions' that were reported from Survey 3 to Survey 4, specifically on the relationships between caring and employment. The focus on

transitions, rather than one-off snapshots of existing carers provided data that were not always consistent with commonly held stereotypes, or the results of surveys of self-identified carers. The results from Report 2 indicate that for caring and employment:

- 75% of the women in mid-life who were surveyed did not provide care and those that did were almost three times more likely to be caring for someone living elsewhere than living with them
- More than half of those providing care in the two surveys did not do so at both surveys, suggesting that caring roles are transient and changeable
- For more than half of those providing care, the intensity of caring remained stable. If it changed, it was more likely to increase
- Women not in the labour force increased from 33% to 39% between the surveys, but a substantial number of them did unpaid work. If their employment status changed they were more likely to start part-time
- Those in the labour force were more likely to be full-time, and part-time workers were more likely to stop work than switch to full-time
- Carers were more likely not to work or to work part-time.

The way the study was done allowed for an examination of the impact of transitions to and from the caring role:

- Those who started caring were more likely to cut down on working compared to non-carers
- Women who stopped caring were more likely to increase working than those who did not stop
- Women becoming a carer found it more difficult to manage on their available income than those who did not become carers
- Non-carers were the least rushed or pressured, and number of symptoms experienced and medical diagnoses was highest in the 'continued caring' group
- Levels of physical and mental wellbeing were highest in the non-carers.

The pilot sub study from the ALSWH described in Report 3 was called *Service use and the impact of family caregiving on Mid-aged women* (Watson et al. 2007). It surveyed 355 women and was designed to improve the ability of sub studies to further explore transitions to and from caring, and how health services might lessen negative impacts.

Report 3 contains recommendations about useful revisions to measures to be included in the fifth survey of mid-aged women where the aim is to be able to compare 500 live-in carers with the same numbers of non-live-in carers and 500 women with no caring responsibilities. The revisions included a number that will align future surveys with more standardised measures and the ability to compare the carer cohorts with national norms, for example using items from the Medical Outcomes Study (SF36 and social support index) scales (Ware 1993).

Other useful modifications and additions to the fifth survey are recommended:

- A question about receipt of the carers benefit and carers allowance
- A brief self-rated assessment to help quantify resilience, using the Connor-Davidson Resilience Scale (Connor and Davidson 2003)
- Use the 12-item version of the Zarit Burden Scale (Bedard, Molloy et al. 2001)
- Use the recommended 11-item scale to capture positive aspects of caregiving (Boerner, Schulz et al. 2004)

As well as the specifically commissioned research reports on women in their middle years, the ALSWH has reported in the international literature on findings from the surveys on older women (Lee 2001, Lee and Porteous 2002) and the mid-life cohort (Lee and Gramotnev 2007) as well as on the trends and results across the cohorts at relevant carer conferences (Lucke et al. 2007). Results have included observations of how services for the mid-age group break down after the acute phase of illness has passed, that the most common form of assistance required of the older group was transport, and the factors that reduced their use of community services were that the services were unavailable or unhelpful for the tasks required, perceived loss of control and their spouse's reluctance to accept outside help.

“With the ageing population and the consequent increased need for care, it makes sense to consider policy responses to allow women flexibly to combine paid work and other caregiving responsibilities... (These) could include greater access to subsidised respite care and approaches that encourage the ‘normalisation’ of family caregiving ... in the same way that the impact of caring for children on work life is ‘normal’... (These) would enhance the ability of family caregivers to continue to participate in the workforce ... greater access to carers’ leave ... similar to provisions for maternity leave, would also enable carers to maintain their involvement in work.” (Berecki et al. 2007, p. 26)

The ALSWH group point out that their data can support continuing analyses that investigate unmet need and that further research on the extent and nature of the gap between need and provision is going to be helpful in policy formation and the tailoring of programs to better meet the needs of carers. They warn, in the same way as Bittman et al. (2007), that this level of detailed analysis is important to avoid policy that may tend to focus on reducing public expenditure without taking into account the potential for shifting of burdens onto carers.

#### **6.1.8 Implications for further research from longitudinal studies**

The benefit of a longitudinal studies of large cohorts is the ability to make comparisons such as between men and women, the women who are employed and those not in the labour force, between carers and those not caring for someone, between live-in and non co-resident carers, and between different intensities and duration of caring. Demographic, health and lifestyle characteristics can be used to provide further interpretations of the comparisons between groups.

Bittman et al. (2007) are confident that “informal caring occurs with sufficient frequency to sustain the statistically meaningful study of the transitions that underpin the ‘caring career’ – the events of beginning, continuing and ending informal care – opening the way for a rigorous study of the effects of informal caring on the providers of care.” (p. 268)

The potential for shaping Australian social policy by these more rigorous studies is strong. The high growth rate in the number of people aged 45-64 over the next decade presents the distinct possibility of increased numbers of family carers for community-dwelling older people, and demands on the provision of informal care may lead to higher rates of relationship breakdown than were experienced in the past. The coherent approach already seen in the two longitudinal studies reviewed in this Section can easily be refined and used to monitor and mediate negative social impacts and strengthen the role of informal care, rather than over-burden it.

The ALSWH group point out that flexible working hours, access to a range of affordable formal support services and being able to share the load with other family members will prove to be the key to women continuing in their caring roles and offer potential for more working men to accept a higher profile in family caring activity.

The HILDA-based research consortium point out that “knowing how to reduce the personal costs of informal caring is becoming an increasingly urgent issue ... It will be important to continue the investigation of the circumstances that sustain people in these dual roles, to support them in appropriate ways and minimize the deleterious effects for individuals who are prepared to care.” (Bittman et al. 2007, p. 269)

There are also indications from the studies of large population samples of how smaller scale studies and routine data collections might be made more useful by allowing comparisons with national figures and by using standard methods of describing caring.

For example, the ALSWH has used a Care Index (Lucke et al. 2006, p. 6) that combines the answers to questions on the frequency and amount of caring to form a scores (1,2,3,4,6 or 9) that are used to group the women into low, medium and high classifications. The classifications are a practical way that the variations in the carer role can be captured.

The HILDA classification serves a similar purpose but is calculated differently. It classifies the variations in the carer role into 'lighter' = less than 5 hours/week, 'medium' = 5-20 hours, and 'intensive' = 20+ hours/week. Joint work between the two research groups could be commissioned to investigate the benefits of reconciling the classification systems or to recommend a common approach for use in other surveys or routine data collections.

### **6.1.9 The changing context of informal care**

The policy changes that led to the growth of home and community based services have reflected a mixture of social, health and economic goals. The rationale of most recent policy is to delay or prevent functional impairment and subsequent nursing home admissions, and behind the 'prevention' agenda was an important idea promoted through work on what is known in the literature as the 'compression of morbidity' hypothesis (Fries 1980). This theory promoted the value of preventive interventions for older people and raised the possibility of reducing cumulative lifetime morbidity. Since chronic illness and disability usually occur in late life, the theory suggested that cumulative lifetime disability could be reduced if primary prevention measures postponed the onset of chronic illness, while decreases in health risks may also increase the average age at death.

"The hypothesis predicts that the age at the time of initial disability will increase more than the gain in longevity, resulting in fewer years of disability and a lower level of cumulative lifetime disability. There is some controversy in this hypothesis with some contending that healthier lifestyles may actually increase morbidity (and health expenditures) late in life by increasing the numbers of years with chronic illness and disability." (Binns 2007)

This change in the morbidity profile has clear implications for there being a growing need for carers looking after very old people with a range of degenerative conditions, and is confirmed in the recent publication of the AIHW on the burden of disease and injury in Australia in 2003, which stated: "The rate of disability will actually decline in most age groups, except for those 80 years and over, where it is expected to increase and thereby offset some of the gains for younger age groups. The growing rate of disability in the oldest age group mostly comes from expected increases in diabetes and neurological conditions." (Begg et al. 2007, p. 8)

The most relevant example of the increased burdens of disease from increased longevity is associated with dementia, as described by AIHW (2006). "Because Australia's population is ageing, there has been growing recognition that dementia represents a significant challenge to health, aged care and social policy. This report estimates that the number of people with dementia will grow from over 175,000 in 2003 to almost 465,000 in 2031, assuming the continuation of current dementia age-specific prevalence rates." (p. xii)

In terms of the social impact these changes are likely to make, Access Economics (2003) for Alzheimer's Australia estimated that growth of 6% per annum in the HACC program would be required to keep up with increasing demand (even after a 20% top up for current unmet need), plus additional respite services will be needed to better support informal caregivers (p. 6).

So the increase in lifespan has not been matched by an extension of health, and the extra years are spent with disability, disease and dementia, creating a challenge for social policy in making the end of life worth living for both carers and their care recipients.

The success of medicine in keeping people alive and the prevalence of degenerative disease with age have led to an expansion of morbidity, not a compression. Acute forms of death have been converted to chronic death or disabilities as heart attacks become heart failure, stroke leads to vascular dementia and cancers become chronic disabilities (Brown 2007).

The AIHW burden of disease study drew out the obvious implications for services: "Ageing of Australia's population will result in increasing numbers of people with disability from diseases more common in older ages such as dementia, Parkinson's disease, hearing and vision loss, and osteoarthritis. This will increase demand for services in the home, community care, residential aged care and palliative care sectors." (Begg et al. 2007, p. 8)

There are also expected to be changes to the profile of available carers in the future. The AIHW published a study on the future supply of informal care from 2003-2013 (Jenkins et al. 2003) where they estimated that the informal carer sector provides the equivalent of one million full time positions, and informal carers provide 77% of all the care that enables people with disabilities to stay at home. The study points out that structural and numerical ageing of the population signals higher demand for primary carers and heightens concern about the circumstances of a growing number of older carers. Becoming unable to care can cause significant anxiety and practical difficulties for older carers in particular

In the AIHW study on *The future supply of informal care 2003-2013* (Jenkins et al. 2003) it was estimated that the informal carer sector provides the equivalent of one million full time positions, and informal carers provide 77% of all the care that enables people with disabilities to stay at home. This contribution of the household sector has an imputed value of approximately \$28.8 billion, and \$19.3 billion of this is the estimated value of the work of unpaid carers.

The study points out that structural and numerical ageing of the population signals higher demand for primary carers and heightens concern about the circumstances of a growing number of older carers. Becoming unable to care can cause significant anxiety and practical difficulties for older carers in particular.

Over 50% of partner and parent carers said that they could offer the best available care for their family member, confirming the widespread preference for care in the community. Overall, 79% of primary carers in 1998 lived with their care recipient. The rate of co-residency among primary carers of people aged 65 years or over is somewhat lower (62%). Future provision of informal care to people aged 45 to 64 years, in particular, could prove vulnerable to higher rates of relationship breakdown than has been evident in previous generations.

The number of people aged 10 years or over in need of ongoing assistance is projected to increase by approximately 257,100 persons (22%) between 2003 and 2013. Assuming all other factors are held constant, in 2013 the ratio of primary carers to the population in need of assistance from a primary carer will have declined from the ratio observed in 1998 from 43 primary carers per 100 persons with a severe or profound restriction to around 40.

This projection is driven by high growth in the age groups from which large numbers of primary carers are traditionally sourced, counteracting the effect of a moderate reduction in the proportion of working-age women who are willing to reduce paid work to care compared to 1998.

Flexible working hours, access to a range of affordable formal support services and being able to share the load with other family members will prove to be the key to women continuing in their caring roles and offer potential for more working men to accept a higher profile in family caring activity.

A 64% increase in lone person households over the past 12 years, and predictions that this trend is set to continue, will lead to a shortfall in the number of primary carers in 2013, relative to 1998. The scenario in the AIHW (2004) report suggests it may be around 32 primary carers per 100 persons. Access Economics (2005) clearly summarised the findings on the changing context of informal care in its report on *The Economic Value of Informal Care for Carers Australia* (described below), with commentary on the methods used:

*“The AIHW and the National Centre for Social and Economic Modelling at the University of Canberra (NATSEM, 2004) have both produced projections of future demand and supply of informal care by extrapolating out from 1998 SDAC data and adjusting for possible social trends.*

*Both the AIHW and NATSEM have recently conducted modelling on possible future trends in the number of informal carers. Given the uncertainty about the effect of social trends on people’s need for and propensity to provide care, these alternative projections are best seen as possible scenarios, rather than predictions or forecasts about the most likely outcome.”*

The AIHW work by Jenkins et al. (2003) used a scenario approach to estimate the supply of informal carers in the years 2003, 2008 and 2013. The model took rates of informal care provision for different population sub-groups, stratified by age, gender, labour force status and living arrangements, as reported in the 1998 SDAC. In the baseline scenario these rates or propensities to provide care are held constant for each sub-group. Allowing for projected changes in Australian demography, labour force participation and living arrangements over the years 2003 to 2013, estimates can be generated of the total number of people in each population sub-group in the future and hence the number of carers.

The AIHW model does not explicitly model the demand for informal care. By holding rates of informal care provision constant for each cohort, an implicit assumption of the modelling is that the current amount of informal care represents equilibrium between supply and demand. This may be because all demand is met, so that the current balance between formal, informal and no assistance is optimal. Alternatively, if the supply of care is always constrained below demand, due to rationing of formal service places and the choices of informal carers to offer care, supply projections will also be a proxy for the actual amount of informal care provided.

Scenario analysis was conducted to show how the projected supply of carers would differ if social change reduced or increased the propensity of particular groups in society to provide care. Specifically, the scenarios considered were:

- an overall decline in the propensity of people to care, represented by a 20% across-the-board decrease in carer rates;
- a decline in the propensity of women to reduce paid employment in order to provide care, represented by a 20% decrease in the proportion of women reducing paid employment to care;
- an increase in the availability of carers due to converging male and female life expectancy, represented by a 20% increase in carer rates in 60+ age group or spouse carer populations.

The results of this modelling show that, of these single-effect scenarios, only an overall decline in propensity to care would have a marked impact on the number of primary carers in 2013 (Access Economics 2005, pp. 33-34). This indicates the importance of continuing to develop a range of social programs that aim to support and sustain the role of carers.

### **6.1.10 Interplay of informal care and use of formal services**

In the series of population surveys on ageing disability and carers (SDAC) by the Australian Bureau of Statistics (2003), the vast majority of people who reported an ongoing need for assistance received that assistance from a mixture of unpaid carers and formal services. Most people rely on family or friends for this sort of assistance.

This is particularly the case for people with higher levels of needs. Based on the most recent data on the use of care packages, a high percentage of care recipients under the EACH program did not live alone (76%) and this reflects the importance of informal care arrangements in supporting a high-care recipient in their home. Most EACH package recipients (90%) received assistance from a carer; 74% had a co-resident carer, 16% had a carer who did not live with the care recipient, and 10% of care recipients did not have a carer (AIHW 2007, p.53).

#### 6.1.11 The economic value of informal care

A report on *The Economic Value of Informal Care* by Access Economics (2005) for Carers Australia used the data from the ABS survey to examine the amount of informal care being provided in Australia in order to place a dollar value on the work of informal carers. This was described as “the first step in evaluating whether the current usage of informal and formal care models is socially optimal, in terms of both efficiency and equity.”

The report identified Australia’s carers, provided a profile of carers and the care needs of the people they care for, based on the data from the national Survey of Disability, Ageing and Carers (ABS 2003). It used two measures of how this time spent by carers could be valued (opportunity cost and replacement cost). The estimates for the relative value of informal care were 0.6% of estimated GDP for 2004-2005 by the opportunity cost method (or \$4.876 billion) and 3.5% using replacement cost (or \$30.548 billion).

The report went on to quantify where possible, other effects of informal care that should be included in a full account of the costs and benefits of alternative care models, examined the level of public (Government) support for carers relative to other models of care, and outlined the questions and challenges that face policy makers. A final section provided a case study of the care needs of people with severe osteoporosis.

The policy challenges included the projected decline in the ‘caretaker ratio’, described as “a crude indicator of the number of daughters available to provide care to her ageing parent(s)” - currently around 2.5 ‘daughters per parent’. “Under current population projections (high, medium and low) the ratio will start to decline substantially between 2010 and 2025, continuing to decline to 2050. However the sharpest falls will not occur until the mid-2020s, so there is little impact by 2013, the latest year of the AIHW projections.” (p. 35)

The Taskforce on Care Costs (TOCC) is supported by Australian business and non-government stakeholders and was established to investigate the financial cost of care and how it affects workforce participation, and to promote reforms within a policy framework of financial sustainability, equity and choice. (<http://www.tocc.org.au/>) Between 2005 and 2006 TOCC released reports on public policy reforms to assist working carers to better balance their work and caring responsibilities, by identifying the direct relationship between reduced workforce participation and the high cost of care, and proposing financial policy reforms to alleviate this tension. In November 2007 TOCC released its latest report on the work/care dynamic for carers. *The hidden face of care: Combining work and caring responsibilities for the aged and people with a disability* gives a picture of the experience of combining work and aged and/or disability care. ([http://www.tocc.org.au/media/Final\\_TOCC\\_2007\\_Report\\_The\\_Hidden\\_Face\\_of\\_Care\\_16\\_Nov\\_2007.pdf](http://www.tocc.org.au/media/Final_TOCC_2007_Report_The_Hidden_Face_of_Care_16_Nov_2007.pdf))

The methodology for the research behind the report comprised: a literature review of current financial and policy supports for working carers, both domestically and internationally; quantitative research, namely a random sample national survey (conducted by Newspoll) of working age Australians, and working carers (of the aged and people with a disability), on the relationship between work and care, and remedial strategies; and qualitative research with five focus groups with working carers and a roundtable with experts from peak carer groups on the experience of the work/care dynamic and options for improvement.

The findings from the research for *The hidden face of care* are presented in three sections covering: the policy landscape in Australia; facts and figures; and the voices of formal and informal carers. Conclusions are drawn at the end of each section along with recommendations for action.

In summary, there is an unmet need leading to reduced levels of workforce participation and the high cost of care. One in four carers of the aged and/or people with a disability have reduced their hours of work because of the cost of care. The report advocates that Government should provide additional financial support to relieve the cost of care, and continue to address the situation where carers currently feel undervalued and misunderstood by employers and co-workers. 34% of carers surveyed said that their job/career has suffered because of the competing demands of their caring responsibilities, and they feel that support services are inadequate and fractured across Government departments, as well as Federal and State/Territory Governments. Government financial supports for carers should not be viewed as welfare, but as a strategy to enable workforce participation.

### **6.1.12 Summary of key findings from carer surveys on the changing context of informal care**

Changing population characteristics that will influence the need for carer support services include:

- Increasing rates of relationship breakdown
- Estrangement of parents from adult children
- Reduced family formation among young adults
- Widespread altered role perception among women
- A large increase in lone person households

These trends have to be put in the context of accessible formal services being able to substitute for a primary carer. Considerable resources from wider social networks and formal services would be required to compensate for a lower ratio of primary carers to persons in need of care.

There is concern about the growing numbers of older carers. Primary carers over 65 years of age suffer higher levels of severe or profound restriction in the activities of self-care, communication or mobility than their younger counterparts. This concern confirms the importance of psychosocial interventions and the ability to detect depression. Becoming unable to care for a life partner or dependent son or daughter can cause significant anxiety and practical difficulties for older carers.

The various projections do not necessarily signal higher numbers of people with unmet need for assistance because affordable, accessible formal services can substitute for a primary carer. Expanding the range and availability of different types of support for care recipients as well as their non-resident carers will be necessary in order to offset the increase in lone person households.

However, less intense care from a wider network of carers could be problematic for people who require constant supervision and assistance with core daily activities. Given the intensity of caring work performed by primary carers, considerable resources from wider social networks and a wider array of formal services will be required to compensate for a lower ratio of primary carers to persons in need of assistance. Making that increased assistance also less complex and intrusive for the family is the main issue for the design of carer-friendly service interventions and a key to the 'integration' problem.

The system design issue is complex as it involves the relationship between informal and formal care services, and can be best understood within a framework as suggested by Fine (2007) that describes the 'social division of care'. Access Economics (2005, p. 37) pointed out that "in some instances formal and informal care operate as substitutes; a person without access to informal care may instead seek assistance through formal care providers. In other scenarios the two types of care may be complementary; with specialised formal care (such as particular medical

interventions) supplementing the provision of other personal care needs through informal carers (Jenkins et al. 2003).”

The results of the modelling work and longitudinal studies emphasised that the main risk is an overall decline in the ‘propensity to care’, pointing to the importance of the issues such as those raised by the Taskforce on Care Costs (2007), on understanding the circumstances that sustain people in employment and caring roles and of developing policies aimed at minimising the deleterious effects for individuals who are prepared to take on a carer role.

### 6.1.13 Current research projects

With funding from the Department of Families, Community Services and Indigenous Affairs, Professor Bettina Cass is directing a study on *Active Ageing: Inter generation transfers, caring networks and policies maintaining participation of older Australians and their carers*. The objectives of the research project are to analyse the key risk and protective factors relating to economic and social participation and active engagement in social networks of older people and carers, and the role of care-giving in maintaining participation. This project will identify the factors facilitating economic and social participation in later life. This is an important issue, given the association between socio-economic status, economic and social participation and health outcomes in later life for older people and carers.

Related research under this program at the Social Policy Research Centre is on *Young Carers (Costs, Impact on Welfare)*. Defining young carers as children and young people up to the age of 25 who provide informal help, support or supervision on an on-going basis for a family member or a close friend with one or more disabilities or severe illness (using ABS definitions), this project will identify levels of participation in education, training and employment and in friendship and other social/cultural/sporting networks of young carers.

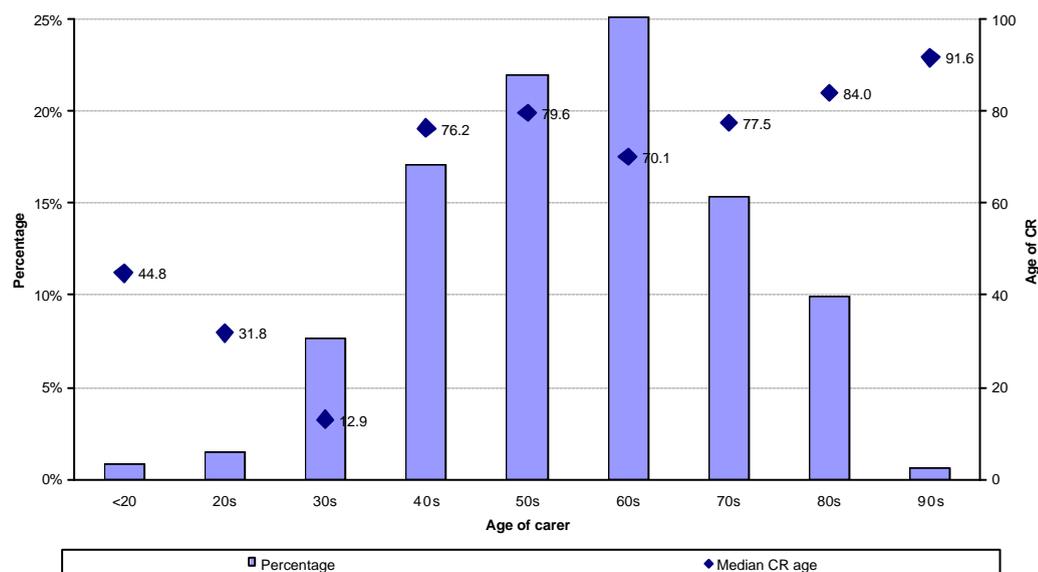
Where data are available, comparisons are being made in that study with young people without care-giving responsibilities. The findings will be used as indicators of the level of social, educational and labour market connectedness/disconnectedness of children and young people who provide informal care, and will also be used to assess the longer-term costs of care for young people with respect to their educational attainment, employment and market income opportunities.

## 7 Carers who are currently seeking respite and other community care services

The Carer Eligibility and Needs Assessment (CENA) project was conducted in 2006 (Ramsay L et al. 2007). The study was undertaken to develop a standard national carer assessment tool. One aspect of the CENA study was a field-test of the draft instrument in 16 agencies in New South Wales, Victoria and South Australia that represent the range of respite and support services available to carers. Half of the participating agencies were Carer Respite Centres and half were service provision agencies. In total, 805 carers were assessed and these assessments provide a rich source of data on carers seeking carer respite and other community care services. A brief overview of the profile of these carers is presented below.

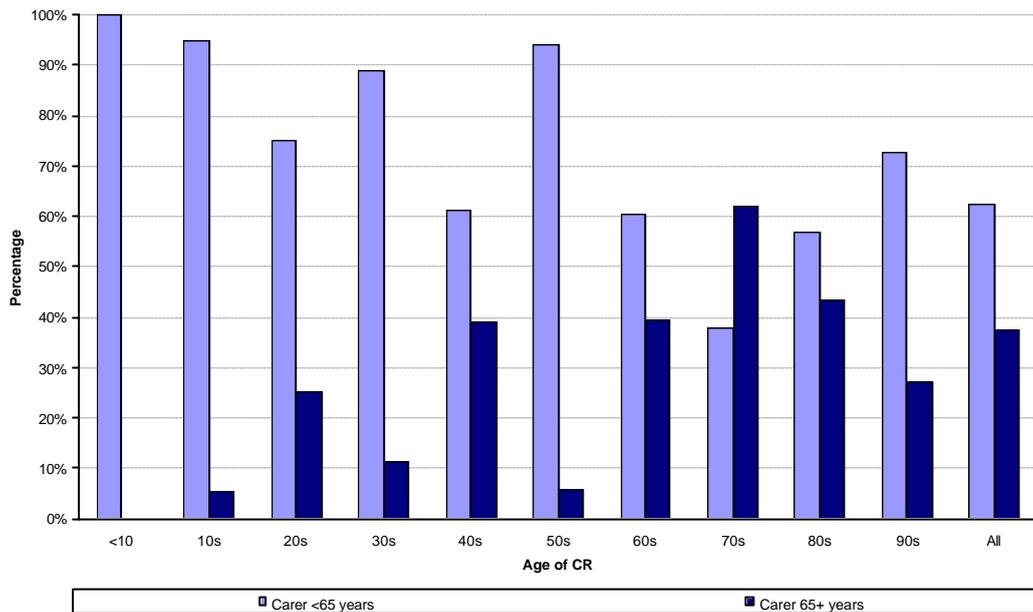
Figure 2 shows the age profile of these carers and the people that they care for. One in four carers assessed in the CENA study were in their 60s and a further 22% were in their 50s. For these two groups, the average age of the person they were caring for was 70 and 80 years respectively. Ten percent of carers were aged less than 40, with one percent being aged less than 20. These groups were caring for younger people, with carers in their 30s typically caring for children and young adults. One in four (26%) carers were 70 years or older and they were typically caring for someone of a similar age.

**Figure 2 Findings from the CENA study: age of carers and the person they care for**



This same information is presented in Figure 3 but this time the figure is based on the age group of the care recipient (CR). It will be seen that, as the age of the CR increases, the more likely it is that they are cared for by an older carer. This is most pronounced for CRs in their 70s, the majority of whom are cared for by their partners.

**Figure 3 Findings from the CENA study: age of care recipient by age group of carer**



This is consistent with the carer relationships shown in Figure 4. Nearly half (43%) were caring for their partner while 29% were caring for a parent. Fourteen percent were caring for their child. Only 2% of carers were friends/neighbours of the person they were caring for. In total, 85% of carers were women and 15% were men.

**Figure 4 Findings from the CENA study: relationship of carer to care recipient**

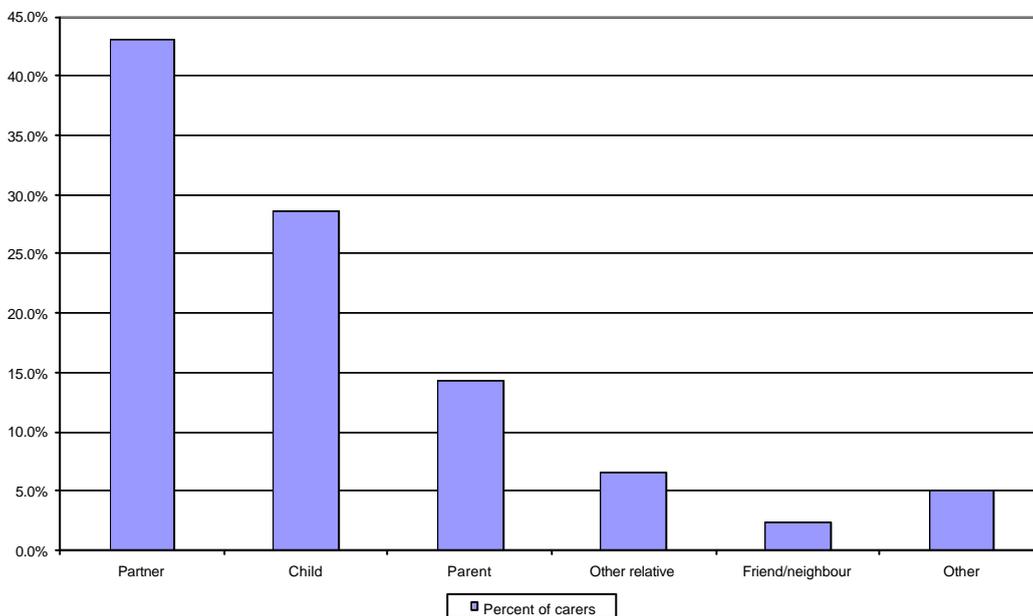
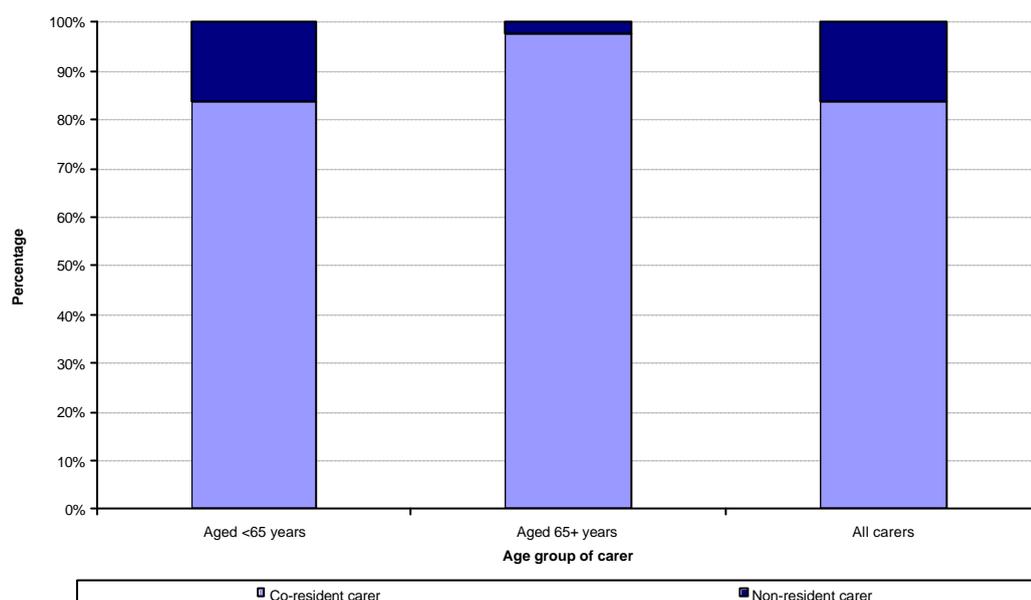


Figure 5 shows carer residency arrangements. Older carers were more likely to live with the person they are caring for. This is consistent with the study findings on carer relationships, with older carers more likely to be caring for a partner and younger carers more likely to be caring for a parent or a child.

**Figure 5 Findings from the CENA study: carer residency status by age group**

Summary data on country of birth is shown in Table 1. Australia was reported as the country of birth in 71% of cases. Two thirds of those born in Australia were aged less than 65 years. This contrasts with those carers who were born in other countries. Carers born in other countries were much older, with over half being 65 years or more.

**Table 1 Findings from the CENA study: country of birth of carer by age group of carer**

Country of birth	Age group of carer					
	Aged <65 years		Aged 65+ years		All carers with COB reported	
	N	%	N	%	N	%
Australia	164	78.1%	79	61.2%	524	71.3%
Other	46	21.9%	50	38.8%	211	28.7%
<b>Total</b>	<b>219</b>	<b>100.0%</b>	<b>132</b>	<b>100.0%</b>	<b>735</b>	<b>100.0%</b>
Country of birth	Age group of carer					
	Aged <65 years		Aged 65+ years		All carers with age reported	
	N	%	N	%	N	%
Australia	164	67.5%	79	32.5%	243	100.0%
Other	46	47.9%	50	52.1%	96	100.0%
<b>Total</b>	<b>219</b>	<b>62.4%</b>	<b>132</b>	<b>37.6%</b>	<b>351</b>	<b>100.0%</b>

Table 2 shows how long carers have been in the carer role. Consistent with national policy, the great majority had been caring for more than 6 months.

**Table 2 Findings from the CENA study: duration of caring**

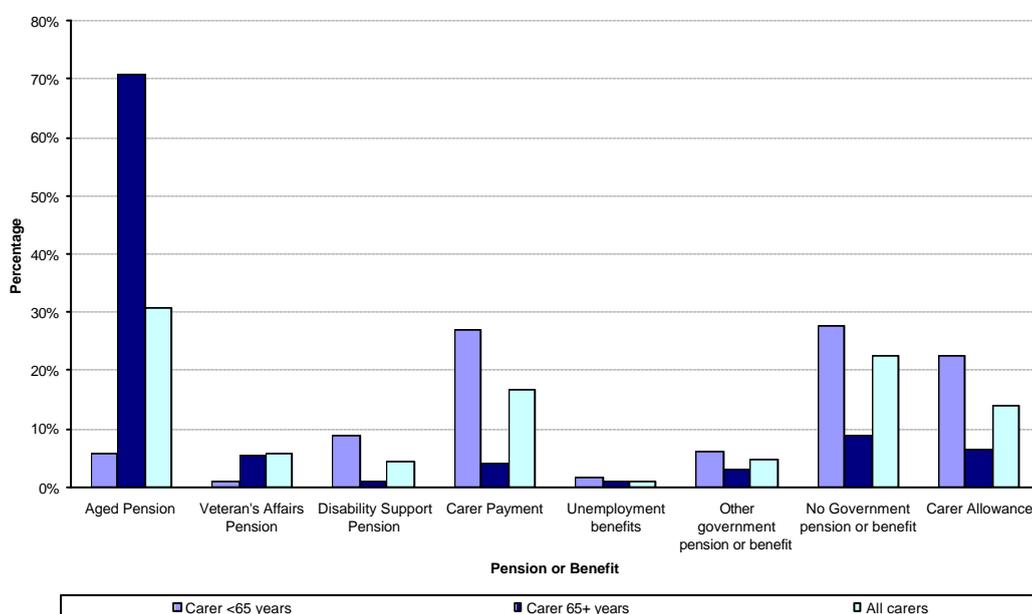
Caring for more than 6 months?	Age group of carer					
	Aged <65 years		Aged 65+ years		All carers	
	N	%	N	%	N	%
Yes	191	97.0%	120	97.6%	582	95.7%
No	6	3.0%	3	2.4%	26	4.3%
Not reported	22		9		197	
<b>Total</b>	<b>219</b>	<b>100.0%</b>	<b>132</b>	<b>100.0%</b>	<b>805</b>	<b>100.0%</b>

The source of income for carers in the CENA study is shown in Figure 6. Three in ten carers were in receipt of an aged pension while a further 30% were receiving carer support (15.7% carer payment and 13.2% carer allowance). Most of the 21% of carers who were receiving no government pension or benefit were less than 65 years old.

In total, 53% of carers had a concession card while 47% did not. Older carers were significantly more likely to have a concession card (78% compared to 40% of younger carers).

The employment status of carers is summarised in Table 3. The majority (74%) of carers were not in paid employment, with 11% working full time and a further 10% part time. But the rate of paid employment varied by age. For those over 65 years, only 2.5% were in paid employment. For those 65 years or younger, 30.1% were in paid employment, with the majority of those in full-time employment.

**Figure 6 Findings from the CENA study: income support by carer age group**



**Table 3 Findings from the CENA study: carer employment status**

Employment status	Age group of carer					
	Aged <65 years		Aged 65+ years		All carers	
	N	%	N	%	N	%
Not in paid employment	127	62.9%	117	97.5%	483	74.2%
Full time	36	17.8%	0	0.0%	70	10.8%
Part time	28	13.9%	2	1.7%	65	10.0%
Casual	8	4.0%	1	0.8%	14	2.2%
Seasonal	1	0.5%	0	0.0%	1	0.2%
Not stated/inadequately described	2	1.0%	0	0.0%	18	2.8%
Not reported	17		12		154	
<b>Total</b>	<b>219</b>	<b>100.0%</b>	<b>132</b>	<b>100.0%</b>	<b>805</b>	<b>100.0%</b>

Assessors in the CENA study could choose more than one option in identifying the circumstances that triggered why the carer sought services (and therefore received an assessment) and did so for 444 carers. 'Carer emotional stress and strain' was the most common circumstance, followed by 'care recipient increasing needs' (see Table 4).

**Table 4 Findings from the CENA study: circumstances triggering contact/ the assessment**

Circumstance	Responses	% of responses
Carer – emotional stress & strain	213	30.5%
Care recipient – increasing needs	149	21.3%
Carer - maintain regular activities	74	10.6%
Carer – acute physical exhaustion/ illness	68	9.7%
Carer – slow physical health deterioration	57	8.2%
One-off event	45	6.4%
Care Recipient – other factors	38	5.4%
Carer - employment issue	24	3.4%
Carer – factors unrelated to care situation	21	3.0%
Carer - return to work/study	9	1.3%
<b>Total</b>	<b>698</b>	<b>100.0%</b>

More profile information on carers seeking respite and other support services is included in the full report of the CENA field test (Ramsay et al. 2007).

The results presented above indicate the level of information that can be obtained from a routine data collection using service-level assessments. This level of aggregated information is useful for service planning as well as reporting. The tables illustrate the carer characteristics from the sample of entry point assessments from the national CENA field trial, showing the profile that can be obtained when an assessment instrument is used in common across agencies and when the instrument is designed specifically to assess the relevant characteristics of carers.

## 8 Carer needs

Section 6 above described what is known about carers in Australia and descriptions of their needs as summarised in various policy documents, studies and reports of surveys. This section summarises the evidence on the needs of carers and in particular the needs of carers of different types of care recipients as presented in the academic and professional literature included in Attachment 3.

There are several Australian academically based research groups that have published in academic and professional journals, covering both general needs of carers and particular care recipient groups, plus individual reports from carers in professional journals that serve to highlight needs through one example.

Several groups in Victoria have contributed to the profile of research on carer needs, including a series of reports from 1997 onwards that grew out of the Victorian Carers Program and its surveys of carers and organisations (Schofield et al. 1997, Nankervis et al. 1997, Bloch and Nankervis 2001).

Morse and Messimeri-Kiandis (1998) examined issues for women carers of Australian Greek families, and from the nursing perspective a group at Deakin University has looked at the health and well-being of older carers (O'Connell et al. 2003) coping strategies of carers of stroke patients (O'Connell and Baker 2004).

Ken Pakenham and researchers at the Behaviour Research and Therapy Centre in the School of Psychology at the University of Queensland have conducted research in the caregiving area and investigated stress and coping models in multiple sclerosis (Pakenham 2001, 2002), and has integrated the results of six samples of caregivers to elaborate a sophisticated model of distress and coping for carers (Pakenham et al. 2005).

The Centre for Social Research at Edith Cowan University in WA, as part of an evaluation for the Australian Red Cross Older Carers Program, examined levels of satisfaction between different carer types (Northcote and Hancock 2005) and barriers to accessing respite in particular for the younger disability group (Hancock et al. 2006).

In the disability support sector Cummins (2001) has examined the needs of family members of providing care for children with a disability, in terms of stress, reduced quality of life (QOL) and depression. Cummins is based at Deakin University and has used the *Personal Well-being Index* in a number of different contexts and has built it into a recent survey for Carer Australia (Cummins et al. 2007).

Llewellyn et al. (2003) investigated the lifetime caring experiences of 64 older parent-carers of adults with intellectual disability and the factors which influence their patterns of service use, Stollznow Research & Insights Advisory (2005) examined the needs of single parent carers of children with disabilities, and Noble et al. (2007) examined services and unmet needs for children with disabilities in the Illawarra.

Single case studies and descriptive approaches to carer needs have been used to highlight carer issues in a range of professional settings. These have included hospital settings (Williams 2007), with GPs (Nankervis et al. 2002), in palliative care (Pierce 2006), with neurodegenerative conditions (Aoun et al. 2006), in pharmacy (Light 2002), speech therapy (Hersh and Owen 2002, Tait and Cutler 2005), in aged care assessment around issues of abuse (Livermore et al. 2001) and for the consumer movement on young carers (Hertel and Byrne 2005).

## 8.1 Summary of the review literature of the needs of carers

Attachment Two summarises the review literature on the needs of carers. The majority of reviews cover the carers of people with dementia. Other reviews cover cancer and the palliative care phase of illnesses, chronic conditions, life-long disabilities and mental illness.

There are no major differences highlighted in the review literature between the carers of different types of care recipients. There are some expected differences in the need for support and practical assistance arising from facing the emotional pressures of dealing with challenging behaviours in people with dementia. The experience of bereavement for carers facing the death of the care recipient has its impact and for those dealing with complex technical tasks in the course of caring activities for the chronically ill there is a need for practical assistance and support.

The types of needs that are described within the different reviews within the sub-sets of types of carers (mostly classified by the type of care recipient, plus working carers, young carers etc) shows the commonality in the types of needs and the range of the measures that were reported in the literature to describe those needs. They are common across all the different types of carers:

- Ways of coping and measures of health and well-being (Gottlieb and Wolfe 2002)
- Admission to residential care, depression, carer stress and general health (Black and Almeida 2004)
- Needs of carers with a diagnosis of a major depressive disorder (Cuijpers 2005)
- Self-efficacy and hardiness of spousal carers (DiBartolo 2002)
- How and why some dementia carers adapt over time whereas others do not (Dunkin and Anderson-Hanley 1998)
- Ethical issues facing carers and the relationship to carer burden and psychosocial impact (Hughes et al. 2002)
- Race, ethnic and cultural differences in the caring experience (Janevic and Connell 2001)
- Associations of carer stressors and 'uplifts' with subjective well-being and depressive mood (Pinquart and Sorensen 2004)
- Correlates of carer physical health (Pinquart and Sorensen 2007), physiological and health indicators and self-reported health (Vitaliano, Zhang and Scanlan 2003)

The non-dementia reviews covered similar domains in examining the concepts of burden, stress, depression and quality of life, physical and psychological well-being, social life, work life, and financial situations.

All the reviews covered similar domains in examining the concepts of burden, stress, depression and quality of life, physical and psychological well-being, social life, work life, and financial situations. The reviews that paid particular attention to the development and use of carer needs assessment instruments referred to the same issues and domains (Guberman et al. 2003). Other reviews that comment generally on how professional groups can improve their practice in meeting the needs of carers (e.g. Plowfield 2000) have mostly been excluded in the Tables.

None of the reviews of needs produced findings that were counter-intuitive or unexpected in the light of anecdotal evidence or studies of specific types of carers. There is more variability in the conclusions and implications for services and for further research activities.

### Implications

Addressing needs, enhancing carer skills and maintaining them in their roles are all assumed to be important, but finding out what works best to redress deficits requires long term and large scale studies, and as one review commented, "we would suggest that cohort studies would be better

suiting to clarifying the factors that more closely predict the development of clinically relevant (psychological symptoms), service utilization or institutionalization.." (Black and Almeida 2004 p.311)

In responding to these findings, the Australian research on carer needs has the benefit of large scale population surveys and relevant cohort studies in the Survey of Disability Ageing and Carers, the Australian Longitudinal Study on Women's Health and the Household, Income and Labour Dynamics in Australia survey as described under Section 6.

Given the variability of ways of describing carers' characteristics, even *within* a common diagnostic group such as dementia, it is not surprising that a common theme of the review literature was a predictable set of methodological caveats.

The lack of standardised ways of capturing particular or generalised carer characteristics was consistently noted, such that "the interpretability of the cumulative body of empirical findings on carer coping is questionable." (Gottlieb and Wolfe 2002 p.325) The descriptions of the particular nature of their needs, stressors, burdens, strengths, approaches to their tasks, ways of coping, quality of life and well-being are not easily made comparable, so the "diversity of issues and wide range of outcome measures precluded quantitative analysis and synthesis." (McKeown et al. 2003)

The first steps towards the use of more standardised ways of capturing the relevant domains of carer needs, risks and strengths and factors affecting the sustainability of their roles have been taken in Australia with the development of common assessment tools under the National Respite for Carers Program and the community care reform strategy as described in Section 7.

## **8.2 Summary of the study literature of the needs of carers - general**

Attachment Three (page 130) summarises studies on the needs of carers. Table A12 summarises papers dealing with carers in general. The body of literature on studies of carer needs in general has been focussed more around the particular conditions of care recipients as described in the following sections. The aims of studying carer needs have mostly been to characterise different types of carers based on the particular demands of their role, given the condition and characteristics of the care recipient.

Studies of carer needs 'in general' are mostly population surveys or studies reported at the level of small scale local surveys and anecdotal reports. Relatively few studies at the smaller scale on general needs are published in the academic literature. They are intended to highlight carer issues for the formal support systems and produced in the form of reports such as those documented in Section 6.

The international literature on studies of carer needs in general has been extensive and is covered by the reviews noted in the previous section. Studies examined the concepts of burden, stress, depression and quality of life, physical and psychological well-being, social life, work life, and financial situations. Two bodies of work on carer burden are worthy of separate mention and had their origins in the period prior to that covered in the current project's search strategies. They marked a turning point for understanding carers' needs in the sense that they were strongly empirically based and contained both traditional concepts of 'burden' and elements representing positive aspects of the carer role.

The significant conceptual shift in research on the needs of carers was marked by a paper by Lawton et al. (1989) on measuring 'caregiver appraisal'. The term was intended to be more neutral (less negative) and was used in investigating the carers' own appraisal of the caring process. This work built on a research and service-oriented multilevel assessment instrument first described in 1982 (Lawton et al. 1982) and led to the inclusion of new dimensions that took this area of need assessment beyond the traditional ideology of burden, to include satisfaction, impact and mastery.

The research that underpinned the conceptual shift was based on a psychometric study of 632 carers in a respite research project. It clarified the inter-relationships between the feelings of distress and subjective burden (poor health, isolation, loss of control etc), the impact on the carer (lifestyle demands, negative feelings, lack of privacy and space) and mastery and satisfaction with the ability to perform the job well.

The empirical approach to measuring the impacts of the carer role has also been strengthened by the continuing development of the Zarit Burden Interview, originally described 1986 in a paper on a longitudinal study of the subjective burden of husbands and wives as carers (Zarit et al. 1986). The Zarit Burden Interview (ZBI) has become the closest the carer support services sector has as an 'industry standard', generating many further studies and translations in particular to support a body of work in Japan (e.g. Arai et al. 2002). The use of the ZBI to investigate the mental health impact of caring has led to important refinements with service implications for screening and assessment tools including work on the validity of statistically derived cut-off scores to help in identifying carers at particular risk of depression (Schreiner et al. 2006).

In the Australian context, the health and wellbeing of carers has been investigated in detail in numerous surveys at both national and local levels and by State-based carer organisations, comparatively few have been reported in the academic literature. As most of the studies in the non-academic literature are relatively small in scale, their results cannot be easily reviewed and compared because of the different methods being used, and mostly they serve to develop policy and amplify the basic findings in the national population-based and longitudinal surveys.

At the national level, research on carers' more general needs focused particularly on financial needs, with recommendations to address those needs through improving access to paid work, where possible, and through the social security and taxation systems. There was considerable quantitative research conducted into the extra direct costs arising from disability and caring, which can be met through programs providing disability aids, equipment and consumables.

The research on general carers' needs in Australia prior to 2000 was summarised in the report on the National Survey of Carer Health and Wellbeing (Briggs and Fisher, 2000, p.8). The summary points to carers' general needs being represented before 2000 in three main reports focussed on making an impact in the policy domain: *Listen to the Carers! The Many Voices of Care: Report of the National Carers Consultation to the International Year of the Family Council (1994)*; *Caring Enough to be Poor: A Survey of Carers' Income and Income Needs (1997)*; and *Caring Costs: A Survey of Tax Issues and Health and Disability Related Costs for Carer Families (1998)*. The first of these reports arose from consultations held in 1994 with several thousand carers, covering many issues of importance to them, not just those relating to financial support and provided an evidence base for national and State and Territory programs.

The needs that were covered in early Australian studies included wider (than residential care) care choices; mediating the effects of caring on carers' health and the health of their families; more services and support for carers; and community awareness of carer issues. This mostly qualitative work pointed to the great importance of all these issues, and the need to address them in more depth and with more rigorous quantitative methods.

Building on this earlier work and the Victorian Carers' Program survey, (Schofield et al. 1997), the National Survey of Carer Health and Wellbeing (Briggs and Fisher, 2000) received information from 1,449 carers and found that the physical, mental and emotional health and wellbeing of most carers was poorer than non carers because of their caring responsibilities. As a result of caring:

- over half of all carers suffered a decline in physical health
- one-third of all carers had been physically injured in the time they had been providing care
- two-thirds of carers felt their mental and emotional health had been affected by providing care

- constant pressure of caring, stress, disturbed or lost sleep and providing mobility such as lifting and transferring were the most common reasons reported for affecting health
- around one-third of carers reported that they found it difficult to undertake or delayed having treatment such as visits to the doctor, hospital treatments, operations, and therapies such as physiotherapy, chiropractic or podiatry, because of their caring duties.

Carers Australia has continued its active role in documenting and highlighting different aspects of particular groups of carers' needs, for example with market research on inadequate access to respite for single parent carers of children with disabilities (Stollznow Research & Insights Advisory 2005), and in the mental health area where the focus on carer rights and access to information has been particularly effective in policy and legislative terms (Carers Australia 2006).

A research report funded by the HACC Program and conducted with Carers Queensland was prepared by Pakenham et al. (2005) and called *Carers in Contemporary Australia: Relations among Carer Illness/Disability Groups, Biographics, Caring Context, Coping and Distress*. It mapped the characteristics, stresses and coping strategies of different groups of carers and care recipients. The findings are consistent with those of other stress and coping studies in the carer field, suggesting that background variables, time spent on caring and coping strategies all play a role in shaping psychological distress in carers. In particular, time spent on *Psychosocial Caring* and avoidance coping showed the strongest and most consistent associations with all measures of distress across the two assessment points.

In contrast to the controlled study and highly sophisticated statistical methods used by Pakenham et al. (2005), two qualitative studies in an Australian context are reported in the area of rural and remote service provision (particularly hospital discharge) and the experience of being an indigenous carer. Communication, information and cultural awareness are the main themes. The areas of need in rural and remote settings are information on the requirements for hospital admission, travel, accommodation and care requirements following discharge. Discharge processes need to ensure patients and carers are linked to adequate support services in their home communities (Harris et al. 2004).

For indigenous communities existing health programs are seen as unhelpful because they do not take into account the values and styles of Aboriginal culture and represent an agenda of forced assimilation into the mainstream. Pearce (2000) argues that Aboriginal men could play a far greater role in providing care given the opportunity and with appropriate support by government, policy makers.

The results from the small and large scale studies reveal essentially the same issues of barriers to access and the need for practical assistance that is appropriate to the carers' context and accessible, and are of interest because of their implications for service provision.

The same or similar issues are evident in the international context, where the trans-European study of family carers (Eurofamcare Consortium 2005) interviewed about 6000 carer respondents through six national surveys. This study reported on the areas of the carers' need for support in decreasing order of their significance and across all the national samples they were described as domestic (92%), emotional/psychological/social (89%), mobility (82%), financial management (80%), organising and managing care and support (79%), health care needs (79%), physical/personal care (66%), financial support (36%).

### **8.3 Summary of the study literature of the needs of carers - cancer and palliative care**

Table A14 (page 134) summarises the literature on the needs of carers of people with cancer and in the palliative care phases of life-limiting conditions. Most were one-off studies in a local community and some were reported as part of larger ongoing/longitudinal studies (Visser et al. 2004). The size of the samples of carers ranged from 7 carers of people in Canada with HIV/AIDS

(Stajduhar and Davies 1998) to 178 carers of those with a cancer diagnosis recruited at the time of referral to a hospice homecare service (Mt Olivet) in Brisbane (Kelly et al. 1999).

As the purposes of these studies are to gain insights into the nature of the carers' needs, the methods used are mainly open-ended interviews, focus groups and questionnaires covering their levels of support and impacts on employment and some more standardised measures including scales of health status and carer strain.

The results indicate the practical supports that are helpful, the factors influencing vulnerability and the types of strategies used by the carers to deal with the demands of the role. Some carers felt exploited by the health system (Stajduhar 2003). There were fundamental differences reported between patients' and carers' views about privacy and autonomy (Terry et al. 2006).

Factors that that decreased vulnerability included: continuing previous activities, including work; setting limits on their involvement (e.g., by refusing to be trained to give injections if this is too distressing); and receiving good support from family, friends and professionals (Proot et al. 2003).

## Implications

Good support from home care professionals falls into three categories: related to instrumental, emotional and information needs (Proot et al. 2003). Prompt access, reducing the number of health care providers, improving communication between providers, help with medications, reducing the amount of physical care provided by carers and more time to themselves, and a feeling of being included in decision-making are the examples of what helps reduce the burdens of carers for people with life-limiting illnesses.

Further research on the impact on carers of the different trajectories of illness at the end of life is an example of important work that is yet to be carried out. There are emerging logic models illustrating three trajectories of rapid decline, chronic and intermittent and sudden death, and very poor function, with long term slow decline. A recent description of the model indicates how research could drive policy in an effort to get services right for those sick enough to die. (Dy and Lynn 2007)

## 8.4 Summary of the study literature of the needs of carers - dementia

Table A15 (page 140) summarises the study literature on the needs of carers for people with dementia. This represents the largest body of research on a specific sub-group. The large volume of studies has resulted from recognition of the implications of population projections of the growth in the absolute numbers of care recipients with dementia, and in anticipation of the demographic shifts and social changes in the balance of formal and informal care that are predicted. As a result of those predictions a lot of research continues to be conducted into the needs of dementia carers and on the types of investments that will need to be made in sustaining them in their roles.

The ten systematic reviews of the needs of dementia carers covered a total of 249 studies including (in some cases) previous reviews. Those review publications cover the studies that were found in the current search strategy. No attempt has been made here to take a detailed account of all those individual studies that were the subject the other reviews, or to address the methodological issues or multiple reporting of the same studies. This section is a summary made of the individual studies to draw out the implications for the purposes of service development and further research.

The size of the samples in the studies of dementia carers ranged from 4 in a UK study (Armstrong 2000) to 379 in a Japanese randomised controlled trial (Miyamoto et al. 2002). Like other studies of carers the dementia studies used a mixture of semi-structured interviews, questionnaires, and descriptions of care tasks. The dependent variables were residential care placement and scores

on standard scales such as quality of life measures, ADLs and IADLs, cognitive and depression scales, and strain and burden tools such as the Zarit Caregiver Burden Interview.

## Implications

The needs of dementia carers are for increased day care and respite (Armstrong 2000), help with practical information and behaviour management particularly of negative traits such as stubbornness, unco-operative behaviour and apathy (more than behavioural excesses such as aggression, restlessness or lability of mood). Important reassurance factors for carers were that they knew there was someone to assist them and that their roles could be taken over if they themselves became ill.

"The six highest ranked unmet needs named by carers were (1) to know someone will provide care if I become ill, (2) a telephone hotline I could call if I needed further information, (3) to have time for myself, (4) ways to deal with my stress, (5) to have physical rest, and (6) ways to deal with my feeling of being trapped... Respite was one of the most frequently mentioned needs." (Leong et al. 2003, p.136) In the Australian context, easier access to the domiciliary nursing benefit and the carer payment was highlighted as useful if the criteria could be wider than the need for nursing services (Cahill and Shapiro 1998, p.99)

Service providers were recommended to play a more proactive role in counselling and advising carers about better care options, including the appropriateness and timing of nursing home placement (Cahill and Shapiro 1998 p.99).

Brodady et al. (2005) investigated why caregivers of people with dementia and memory loss do not use services by examining data on 109 carers of people with dementia identified from the Victorian Carers Survey (Schofield et al. 1997). One in three dementia caregivers were not receiving any services and one in four used only one service. Very few were using multiple services. The main reason for non-use was perceived lack of need, followed by care recipient resistance. The presence of a physical disability in the care recipient was significantly associated with service use. Surprisingly, whether or not the GP undertook a service coordination role, service availability and affordability were not identified as major impediments to service use.

The results of the naturalistic observation study by Pot et al. (2005) showed that getting additional help has costs as well as benefits as "the onset of paid home care was associated with increases in family carers' feelings of worry and strain and a worsening in positive affect." (p.216) The results of this study suggest that receiving paid home care "may not be enough to unburden the family carer. Paying attention to family caregivers' concerns when they accept paid home care ... may be necessary for paid home care to become successful in relieving family caregivers' burden." (Pot et al. 2005, p. 218)

In a similar way, Proctor et al. (2002) found negative impacts that can only be offset by a measure of rapport, as there was an association between increased knowledge and higher levels of anxiety (p.1137). "It is clear that education about dementia needs to be delivered in a supportive and sensitive environment where it is possible for carers to explore ideas and share emotional reactions." (p.1138)

Bartlett et al. (2007) in the Dementia Research Mapping Project summarised research findings and trends in the area of social support and care for persons with dementia and their carers over the past ten years. It covered palliative care, activities of daily living, behavioural and psychological symptoms, accessing the perspective of people with dementia, support for carers, housing provision and environmental design, cultural differences in carer experience, and ethical issues in dementia care.

Bartlett et al. (2007) concluded that more research evidence is needed to inform the development of better guidelines, protocols and guidance for dementia care/ services. While the randomised controlled trial is considered the gold standard to determine the efficacy of treatments, qualitative

methods remain an important tool for understanding experiences and for improving user compliance and involvement.

The dementia carer studies confirm the high level of burden and mental distress in spouse carers and the variety of interventions that may be useful in meeting their needs. The range of these effective interventions across the different types of carers is covered in Section 9 below.

## **8.5 Summary of the study literature of the needs of carers - disabilities**

Studies of the needs of carers of people with disabilities have mainly focussed on the parents of children with intellectual and physical disabilities, and in particular on challenging behaviours. They are summarised in Table A16 (page 147). The methods used have ranged from telephone interviews investigating the importance of paid leave with 1105 parents (Chung et al. 2007), through face to face interviews investigating the needs of sibling-carers (Dew et al. 2004), studies using structured questionnaires (Adams and Allen 2001, Martin et al. 1997) and burden and behavioural and family functioning measures (Maes et al. 2003, Higgins et al. 2005). Using a literature-based strategy rather than a survey, Cummins (2001) reviewed 4000 studies contained in an academic data base and examined the consequences on family members of providing care for children with a disability, in terms of stress, reduced quality of life (QOL) and depression. "Care givers of people with severe disability are at extreme risk of being highly stressed, clinically depressed, and with a subjective QOL that is way below normal ... Children with disability have a higher risk of abuse... and it would not be surprising to find ... a relationship to the degree of family stress".

On a smaller scale, but with a coherent methodology including qualitative and quantitative methods, Llewellyn et al. (2003) completed a research study funded by the National Health and Medical Research Council, to investigate the lifetime caring experiences of 64 older parent-carers of adults with intellectual disability and the factors which influence their patterns of service use. Reflecting the earlier work on carers' needs, they reported that the carers had poorer physical and mental health than the Australian norm, that those with locally integrated support networks did better, and there was little difference to the NSW population in their use of health services. In drawing out the implications of their findings for policy and practice, the authors highlighted the need for best practice standards in "futures planning", specific targeting of older parent-carers' needs in service development, in professional training, and in the delivery of medical and social support. In a subsequent published article (Dew 2004) this group highlighted the needs of siblings after parent carers had passed away.

In a submission to the Senate Review of the Commonwealth State Territory Disability Agreement in August 2006, Carers Australia (2006) quoted the results of a 2005 study by the University of Queensland and Carers Queensland (Pakenham et al. 2005) which examined the relationships between carers of different disability groups and their caring context, coping and distress. It suggested that the problems encountered by carers of people with disabilities are long term, and not easily redressed. That survey found that 25% of the 1200 carers surveyed were clinically distressed and many of the carers were surveyed twice with a three-month interval, and reported the same distress level at the time of both surveys.

### **Implications**

Consistent with what would be expected by the relatively small numbers in the life-long disability population (as opposed to disability acquired later in life) and the nature of the disability sector (being less professionalised), there is a relative lack of published studies and those that are published use more naturalistic methods.

The implications of the studies are usually couched in terms of policy prescriptions. Most review of needs as described in the literature advocate increased public expenditure directed to the care of people with severe disability, aiming to reduce carers' high risk of stress, clinical depression, and improve their quality of life.

It is not always made clear whether increased expenditure should involve support for formal or informal care as the backdrop to the policy recommendations are usually a perceived and real shortage of resources and resulting unmet needs.

## **8.6 Summary of the study literature of the needs of carers - frail aged**

As summarised in Table A17 (page 149), only a few studies were identified that specifically address the needs of carers of the frail aged as frailty is usually one of a number of descriptors of an older person's conditions. There were additional studies not covered in this section where frailty is one of several reasons for care, for example most often in carers of people with dementia.

A Spanish study of 111 informal carers looked at the factors associated with the positive impact of caring for elderly and dependent relatives (Lopez et al. 2005). It used standardised instruments including the Zarit Burden Interview (Zarit 1980) and the Caregiving Satisfaction Scale (Lawton et al. 1989). "The outcomes related to these positive emotional aspects (of caring) are the following: a better previous affectionate relationship between the caregiver and the care recipient, less use of venting as a coping strategy, being a caregiver by ones' own decision, maintaining the same amount of leisure time than before becoming a caregiver, and not working outside the home. All these factors are related to caregiver characteristics, not to those of the care-receiving subjects." (Lopez et al. 2005 p.92)

A US study located under this heading examined factors associated with 'medication hassles' experienced by 156 family carers of older adults (Travis et al. 2007). This study identified potential factors associated with medication administration hassles, daily irritants, among informal carers who provide long-term medication assistance to person aged 55 or over and used a tailored tool to systematically quantify the 'hassles'.

Based on a major large study in the Program of All-Inclusive Care for the Elderly (PACE) in the US, which is focussed on delaying admission to residential care, the effects on employment from caring for frail elders was examined in relation to ethnicity, patient clinical characteristics and carer characteristics. (Covinsky et al. 2001). They found the patient characteristics that predict a reduction in carer employment are the same characteristics that predict nursing home placement (ADL dependence, stroke, dementia with behavioural disturbance). The paper pointed out the need to better understand the economic costs of caring.

## **Implications**

The studies of the frail aged showed the value of assessing for positive aspects of caring, medication difficulties, the importance of ADL dependence, and the presence of stroke and dementia with behavioural disturbance.

## **8.7 Summary of the study literature of the needs of carers – mental illness**

Studies of the needs of carers of people with mental health problems are used to examine the context of mental health interventions by focussing on the expectations and experiences of families in relation to community mental health service provision (Hodgson et al. 2002). They are summarised in Table A18 (page 151) and investigate the level of satisfaction of the carers in relation to key components of mental health service delivery particularly in the relationship between carers and the principal service provider and the carer role in care coordination.

As with other studies of carer needs the mental health studies investigate the extent of carer involvement, and differing perceptions of patients and carers regarding information and resource needs (in inpatient and community settings), and do so through face-to-face and semi-structured interviews, and specifically constructed scales (Spear 2003) to investigate satisfaction and barriers to involvement.

Studies have ranged from relatively large scale work in Sweden (Ostman 2005) to small studies that have investigated indigenous (Phillips 2004) and CALD issues (Rooney et al. 2006) in Australia.

## **Implications**

Carer response rates can be poor and levels of carer availability and support may vary in settings with different cultural and socioeconomic characteristics, making it hard to generalise about the needs of these carers. However there are now a growing number of carer support programs and comparisons between areas with and without these programs using standardised and routinely administered assessment tools to measure carer needs may highlight if there is any impact for carers of implementing programs to assist them.

### **8.8 Summary of the study literature of the needs of carers – stroke and brain injury**

The key areas of carer need are similar to other care recipient groups, summarised in Table A19 (page 155) and use similar tools to describe the risks of burnout and burden such as the Caregiver Strain Index. Stroke and brain injury studies include the carer's experience of severe and prolonged disability and managing issues such as mechanical ventilation (Scott et al. 2005)

Studies have investigated, for example, which carers of stroke patients living at home experience the highest levels of strain and are at risk of burn-out, and how support could be organised and when this support should be offered (van den Heuvel et al. 2001). They have investigated differences in family stress levels related to the role of the injured person within the family and the severity of the injury (Gan et al. 2006, p. 595).

## **Implications**

The number of participants in studies of the needs of carers of people with brain injury and stroke is often limited, and the needs of this group of carers are more often captured in broader populations of carers. However descriptions of the carer experience are consistent with those in other technologically dependent populations, suggesting that consistent themes are inherent in the complex carer experience and are not isolated occurrences specific to a given patient population.

### **8.9 Summary of the study literature of the needs of carers - other chronic conditions**

The needs of carers of other populations are summarised in Table A20 (page 156). A German survey of 158 carers of people with Parkinson's disease investigated the impact on the carer of the emergence of depression, psychosis or dementia in a person with that condition (Ellgring 1999). The study recommended that psycho-education interventions play a role in restoring lost meaning to the lives of the carers, and that stress prevention programs help patients and carers cope with the daily demands.

In a study in the USA of primary carers of individuals who had been liberated from prolonged mechanical ventilation, anxiety, fear and loneliness and the perceived care burden associated with complex caring was overwhelming for most participants.

The dual roles of carer and employment competed, precipitating physical and mental fatigue, and adversely affecting both caring and work performance. Although they received advice for self-care, the carers had difficulty using self-care strategies for themselves (Scott and Arslanian-Engoren 2005).

The social impact of multiple sclerosis in one county Southern England was examined by a study of 305 patients and 74 informal carers of people with multiple sclerosis (Hakim et al. 2000). The prevalence of depression and anxiety and change in the carers' employment status was recorded.

The authors suggested the need for interventions to reduce social isolation to improve the quality of life of patients and families.

The relationship between emotional distress in caring and the health status in persons with multiple sclerosis was also examined in a study of 133 carers in Italy (Pozilli et al. 2004). The focus was on including the carer in the multidisciplinary team's care plan and patient and carer assessments were used with a one-year follow-up. Carer education was included in the intervention but no details were given of the nature of the education provided and information provision did not affect carer depression. The authors concluded that research should identify carers in need of emotional and other support as the first step in developing appropriate interventions

Some studies are small scale and interpretive, rather than examining a carer population. For example the experience of 17 parents of adolescents with complex chronic pain (Jordan et al. 2007) showed the importance of having a diagnosis and help with the forms of pain relief. The study showed the value of understanding psychosocial and family relationship issues in this group of carers.

Caring after cardiac surgery was examined in particular in relation to gender differences (King and Koop 1999). Women were significantly less likely than men to rely on their spouses for tangible help or emotional support during the post-operative phase, and tended to have a support /carer network more than men (including daughters, daughters-in-law, friends and health care providers), but no primary carer coordinating the effective fulfilment of physical and emotional needs. Care received by men from their spouses more often included both physical and emotional care (being there, listening, supporting). Male carers tended to help with the housework, but wives wanted more emotional support.

## **Implications**

The same implications were described for other chronic conditions as for other types of carers, where attention to the psychosocial domains and the usefulness of sharing the experiences of others in similar situations was highlighted as the most suitable responses to their needs. Most studies concluded that interventions need to focus on the carer and be more specifically developed to meet carer needs.

Studies on the needs of carers of the chronically ill point to the significance of psychosocial assessments. In particular, the work by King and Koop (1999) points to the importance of understanding gender differences and the lack of emotional support experienced by women when the carer is a male who is likely to focus on more instrumental caring tasks. "To support families enduring these hardships, a few cursory words of advice from a physician will not suffice. Rather, thorough psychological counselling and an opportunity to share experiences with others in the same situation are often needed." (Ellgring 1999, p. 20)

### **8.10 The implications for further research from the review of studies of the needs of carers in the community**

There are a number of valuable sources of data in Australia that have yet to be fully utilised for their potential to be a central component within an agenda of research and service development on carers and their support needs. The main limitation to developing a "bigger picture" for research and development in the carer sector is the same as that facing service delivery; the difficulty of unifying the various efforts when they are fragmented between different levels of government, different departments and different programs. The international literature reveals the same limitations.

In the short term there is a need for more standardisation in asking specific questions of carers and about carer support in population surveys and in studies of carer needs in more localised

settings. These more targeted questions can then be used to shape consistency in the work at the 'lower' levels of investigation into the needs and service gaps for carers.

The longer term aim would be to bring a measure of standardisation and consistency into the large amount of localised survey efforts, thereby allowing for more meaningful comparisons to be made across settings and for aggregated data to be more useful for planning and service development.

For example, it is useful for planners responsible for resource allocation at local area levels to know where a region or smaller area stands in relation to national or state figures for the proportion of carers surveyed who are seeking access to better information or more services. There is much that can be done to improve the quality of the information available to the planners of programs and services and those allocating scarce resources, so that the levels of local funding can be better matched to demonstrable levels of need.

In the longer term, and on a larger scale, the quality and level of information that is becoming more available from national surveys and longitudinal studies has the potential to be used to measure the results of changes in a range of social policies and how they make an impact on carers. This should be centrally commissioned research (rather than only investigator-driven) once a set of priorities is determined, in order for it reliably inform policy and service development. It should be possible to line up the central concerns and more local considerations inside a national research and development agenda.

There are already some promising models of how to realise this potential for carers from the work within dementia programs, where coherence and 'harmonisation' of the field is being promoted around effective treatments and interventions, through to training strategies, prevention, social research and policy formulation. The recently published *Dementia Research Mapping Project*, funded under the Dementia Health Priority Initiative (Bartlett, et al. 2007) demonstrates a way of proceeding. A research and development agenda specifically for carer support, using the lessons from the dementia initiative, will be a useful adjunct to the more 'micro' level impacts that can be expected from improving the types and methods of delivery of specific interventions for carers based on using the best evidence of effectiveness.

For example, do social policies that aim to increase social inclusion and access to services, or to provide more material support, or relax stringent eligibility criteria, make a difference? Do changes in programs coincide with reported changes (from longitudinal studies) in the rates of workforce participation, social support or the care index (in the ALSWH) for people in care-giver roles? Do they make an impact on the hours worked and levels of income of carers (in the HILDA survey)? These longer term studies could then be used to help in planning for an ageing population and to understand how best to sustain the supply of informal care in the future.

"While there is a long tradition of studies of how people become 'obliged' to care ... and many cross-sectional contrasts of informal carers and those without caring responsibilities, there have been few studies in Australia which track individuals through the important life course transitions around informal caring. The emergence of large scale longitudinal studies in Australia opens the way for these kinds of studies ... it is possible to use them to study the transition to and from care." (Bittman et al. 2005, p 258)

### **8.11 Implications for practice from descriptions of carers in Australia**

Most health and social programs in Australia no longer see the viability of a simple substitution effect of informal for formal care in the face of increased demand. The further development of carer support services as a key part of the formal support system is inevitable.

However the continued growth and development of this sector needs to be better planned and based on more reliable evidence in order to avoid unnecessary duplication of development efforts and the promotion of ineffective service responses to the growth and complexity of health and community needs.

The challenge in a service development agenda in response to carer needs is to gradually 'harmonise' the central and more local efforts over time in order to better understand what works best for different types of carers and to then connect up the myriad of interventions that are potentially on offer to the carer support sector in way that makes sense to local providers of that support.

This conforms with the wisdom distilled from the investigation of the larger service 'integration problem', that all integration is local and "each integration effort has to be implemented locally in a way that is consistent with the particulars of local systems and personnel ... and successes have been based on local leadership, development of trust, doing what works, etc, rather than top-down directives." (Leutz 2005, p. 9)

## 9 Interventions

Table 5 summarises the evidence from intervention studies. More information on each of these studies is included in Attachment Five (page 183). In addition, summaries of major reviews of interventions are included as Attachment Four (page 158). As this Table (and the following sections) illustrate, the overall evidence on the effectiveness of carer interventions is weak, but promising.

**Table 5 Summary of the strength of the evidence from intervention studies**

Evidence rating	Care coordination	Educational or psycho-educational	Family support	Multi-component	Psychosocial and counselling	Respite care or day care	Support groups	Total
1 - Well supported practice	5	5	2	3	2	1	1	19
2 - Supported practice		1					1	2
4 - Acceptable practice		2		3		4	1	10
5 - Emerging practice	1	5		2			3	11
8 - Carers' views (surveys, interviews)	1	3	3		2	2	2	13
10 - Economic evaluation (incl.service use)			1					1
<b>Total</b>	<b>7</b>	<b>16</b>	<b>6</b>	<b>8</b>	<b>4</b>	<b>7</b>	<b>8</b>	<b>56</b>

Regardless of the intervention, the literature reports contradictory findings. While few studies suggest adverse outcomes for carers or care recipients, the majority report findings that are ambivalent or conditional. However, a significant minority of studies do conclude that interventions for carers are effective, albeit at various levels of evidence.

This is not surprising. The findings summarised in the various attachments to this report reflect the significant methodological challenges in measuring the effectiveness of carer interventions. Four key challenges that influence many intervention studies are discussed below.

### Defining the intervention

Many interventions reported in the literature are poorly defined or not defined at all. Even when well defined, the exact nature of the intervention is rarely well described. The outcome is that 'systematic reviews' are often attempting to synthesise results of what are, in reality, different interventions. In this regard, it is not surprising that they draw different and conflicting conclusions.

As one example, 'respite care' may be planned or unplanned, provided in different locations (home, centre or residential) and provided at various levels of service intensity (one-off, daily, weekly, monthly and so on). There are few reviews that control for different service models or that have attempted to measure dose effects (e.g., is weekly respite care more effective than, say, respite once a month?). Given this, it is not surprising that various reviews and studies report different findings.

This same issue applies to other carer interventions, including (but not limited to) counselling, family support and psycho-education.

## Specifying the target group

As the analysis of carer needs demonstrates in Section 8, carers are not a homogenous group and neither are their needs. Few studies include any rigorous assessment of the needs of the carers receiving the intervention. As such, it is difficult to determine if the intervention being studied is actually required by the carer or whether, in fact, another intervention may have been required.

## Specifying the goal of the intervention

An important related issue is that the goal of most carer interventions is poorly defined in much of the literature. The goal may be variously:

- Carer satisfaction (with the service they receive)
- Domains such as carer stress, burden, anxiety, depression, coping skills and physical health. The assumption in many studies is that the goal of intervention is to achieve improvements in these domains (i.e., that carer interventions are *therapeutic*). Occasionally, the goal is expressed in terms of *prevention* or *protection*, with carer interventions being designed to help prevent carers from developing problems in these domains
- Positive aspects of caring (e.g., satisfaction, self-esteem) are considered in a small number of studies, most published in recent years
- Impact on, and outcomes for, care recipients. These range from the physical and mental health of the care recipient through to measures such as delay in residential placement.

Not surprisingly, the conclusions drawn about the effectiveness of carer interventions are largely influenced by the outcome measures employed. The overall evidence on carer satisfaction is strong – most studies report high levels of satisfaction with the services that carers receive.

The evidence on carer services as therapeutic interventions is more ambivalent – some studies report modest, but important, improvements while others report no change.

As well using standardised outcome measures that are relevant to the goal of the intervention, personalising the goals of clinicians, clients and carers by using a method such as Goal Attainment Scaling (Rockwood 2006 and 2007) is another way that additional clarity and better quality evidence can be introduced in the field of carer support.

There are few good studies on the positive aspects of caring and whether carer interventions can influence these. One review (Pinquart and Sorensen 2004, p447) concluded that 'developing and maintaining sources of positive affect may counteract some negative effects of caregiving and thus protect carer's well-being and mental health'.

Equally, there are only a small number of good studies on impacts for care recipients. While there is good evidence that care recipients rely on their carers, there is only patchy evidence to suggest that specific carer interventions have any impact on the care recipient.

## Research bias and methodological issues

While there is a growing literature on the limits of the Randomised Controlled Trial (RCT) as the 'gold standard' of research evidence, many 'systematic reviews' published to date have only considered the results of RCTs. This necessarily limits both the scope of these reviews and the conclusions that they draw.

Overall, the evidence from 'reviews' is less promising than from 'studies'. While no doubt this is at least partially reflects a level of 'optimism bias' in the reports of off-one studies, it also reflects on the systematic research bias built into the methods of those undertaking systematic reviews.

The reality is that carer interventions are necessarily complex, multi-factorial and often tailored to the perceived needs of both the carer and the care recipient. They do not lend themselves easily to the rigours and the limits of a RCT.

One reason is ethical considerations. For example, most people would find it unethical to deny a request for, say, counselling and respite and (instead) randomise the carer to a control group. This problem is not unique to carer interventions of course. It is a legitimate issue in a range of health and social care and beyond (parachutes have never been the subject of a RCT either).

Another reason is timing. Many studies measure outcomes over relatively short periods (weeks to months). Outcomes for carers may change over time and may need to be measured periodically over years.

Finally, many papers reviewed were more focused on methodological limitations than results. Not surprisingly, more reviews recommended further research than recommended ways to more effectively meet the needs of carers.

### **9.1 Synthesis of findings on the effectiveness of carer interventions**

Results from evaluative research and systematic reviews of the literature (Brodaty et al. 2003, Cooke et al. 2001, Pusey and Richards 2001, Sörenson et al. 2002, Zarit et al. 1999) on existing programs to support carers in their role (educational interventions, respite services, support groups) have not been very conclusive. The services offered do not seem to have an impact on carer burden (i.e., the interventions are not therapeutic).

Ducharme (2006) points out a number of reasons that have been evoked to explain this:

- (a) the outcome measures used have not been sufficiently sensitive to change
- (b) the elements of the interventions have not been specific enough to meet carer needs, and
- (c) as interventions have, for the most part, been multidimensional, the type of evaluation performed was not conducive to determining which components of the intervention were more or less effective.

Instead, interventions whose content is geared towards problem solving and cognitive restructuring produce greater effects and a certain improvement in carer well-being (Cooke et al. 2001). Also, interventions based on an individual approach are more likely to have significant effects than those based on group approaches, the former being better targeted and more intense. To date, few individual intervention models have been the focus of evaluative studies (Gitlin et al. 2003, Mittelman et al. 1995).

Taking into account the limitations of research to date as described above, the key findings across the literature are:

#### **Information giving**

Giving information alone (whether verbal or written) is not effective.

#### **Case management and care coordination**

Although there have only been a small number of studies investigating case management and care coordination and the impact on the carer, the available evidence is promising.

More detail on case management and care coordination interventions is provided in Section 9.2 below.

## **Counselling and psychosocial interventions**

The overall evidence on counselling and psychosocial interventions is positive. However, some studies and reviews report no measurable effects.

There is little evidence on the effectiveness of different types of counselling or on dose effects. Likewise, the evidence on the effectiveness of counselling and other psychosocial interventions for different types of carers (spouses, parents, children, resident, non-resident, employed, young, old etc) is not strong.

More detail on psychosocial interventions is provided in Section 9.3 below.

## **Respite care**

The overall evidence on respite care is that it can provide small benefits. However, some studies and reviews report no measurable effects.

There is little evidence on the effectiveness of different types of respite care or on dose effects. Likewise, the evidence on the effectiveness of respite for different types of carers (spouses, parents, children, resident, non-resident, employed, young, old etc) is not strong.

More detail on respite is provided in Section 9.4 below.

## **Educational and psycho-educational interventions**

The overall evidence on educational and psycho-educational interventions is good, especially for carers of people with dementia, mental illness and disability.

More detail on educational and psycho-educational interventions is provided in Section 9.5 below.

## **Family support interventions**

Reviews of family support services for patients with a mental illness conclude that family support interventions are effective. The evidence from studies of family support interventions is promising, with four dementia studies and a randomised controlled trial in palliative care and bereavement (Kissane et al. 2006), concluding that it is a well-supported intervention.

As with the interventions listed above, there is little evidence on the effectiveness of different types of family support services, on dose effects or on the effectiveness of family support for different types of carers.

More detail on family support is provided in Section 9.6 below.

## **Support groups**

The evidence on support groups at this stage is not established but is emerging. However, one review concluded that social support does not help carers in their caring role:

Participants in support groups in many studies commented on how they much they appreciated talking to other carers who understood their situation, as they had been unable to get this level of understanding from their own relatives and friends. This suggests that the primary carer is rather isolated, as others in the family 'step back' and leave the main responsibility to that one person. From this perspective, support groups are valuable because they put primary carers in touch with each other and reduce the sense of isolation. They are, however, only part of the social support picture: carers also need some sort of practical intervention, such as a family conference arranged by the GP (Leong et al. 2001) to ensure that the responsibility can be shared more fairly and they have back up when they need it. Knowing that someone else is available to step in if they get sick

or need a break is likely to reduce their feelings of anxiety. There may be opportunities to facilitate 'respite care' within the primary carer's own social networks as well as providing more timely access to formal services.

More detail on support groups is provided in Section 9.7 below.

### **Multi-component interventions**

Overall, there is good evidence for multi-component interventions. This is well summarised by the findings of one key review:

Taken together, all caregiver interventions produced a significant improvement (between 0.14 and 0.41 SD units) in caregiver burden, depression, subjective well-being, satisfaction, ability/knowledge and care receiver competence. Psycho-education and psychotherapy had a significant effect on all outcome variables. Multi-component interventions had significant effects on burden, well-being and knowledge. Respite was effective for reducing burden and depression and enhancing well-being. Individual interventions had stronger effects on burden and wellbeing, while group-based interventions had larger effects on care receiver competence. (It should be noted that social support outcomes were not included in the meta-analysis). People caring for a dementia patient were less likely than others to benefit from interventions. Studies with a higher proportion of spouse caregivers (*vis-à-vis* adult children) tended to find smaller improvements in burden, depression etc but greater improvements for care receiver symptoms (Sørensen et al. 2002).

More detail on multi-component interventions is provided in Section 9.8 below.

## **9.2 Case management and care coordination**

### **9.2.1 General findings in relation to case management and care coordination**

#### **Studies**

##### **Well supported practice**

In a Canadian RCT investigating integrated care for older people (Béland et al. 2006), packages of coordinated services tailored to needs were delivered over 22 months to 1230 community-based disabled persons over 64 years of age and their carers. Controls received their usual care. The most important overall impact was in reducing acute hospital utilisation (by 50%) and institutionalisation for participants with increased ADL disability. Carer satisfaction after 12 months was significantly higher than for controls although there were no differences in carer burden between the 2 groups.

A Finnish RCT of a two year intervention program of community care support for carers of people with dementia living in community was reported by Eloniemi-Sulkava et al (2002). The RCT involved case management service by a dementia family care coordinator, which included access to physicians, organising care and services, advocacy, psychological support and counselling for family carers and patients with dementia. At the completion, carers were asked how their lives had changed, and which factors predicted their emotional reactions and life changes. They reported that the support program seemed to have long-term effects and helped carers to return to a normal life with more leisure activities. Spouse carers are more likely to have "emotional reactions of loneliness, depressive feelings and sorrow" following cessation of caregiving whereas "non-spouse caregiving was linked with feelings of relief" (p348), suggesting that different supports are needed pre- and post-care for these sub-groups of carers.

Gaugler et al. (2005) investigated early community-based service utilisation and its effects on institutionalisation in dementia caring with an experimental research design with random

assignment of carers to treatment and control groups. This US study was large, comprising 4,761 dementia carers over a 3 year period. The intervention involved case management (including assessment of carers and care recipients) and care planning, including facilitating access to a range of community-based services largely reimbursed by Medicare. Clients not covered by Medicaid paid a 20% co-payment for the services, to 'instil a sense of cost consciousness' (p179). Interviews were conducted by trained nurses or social workers every 6 months over 3 year period, including a range of outcome measures, including service utilisation rates and institutionalisation of the care recipient. They found that, "for particular types of services, earlier use during the course of dementia caregiving is likely to exert more benefit than if community based long-term-care utilization is delayed" (p184). They recommend that, instead of offering extensive services as a tertiary benefit unlikely to reverse or delay the trajectory toward institutionalisation, "adopting a preventive strategy so that caregivers can adapt to the challenges of dementia care earlier may result in more cost-effective approach to community based long-term-care.." (p184).

In a RCT of early supported discharge after stroke (Teng et al. 2003), the intervention group received a 4-week tailor-made home program of rehabilitation and nursing services while the control group received usual care. The authors reported good outcomes for care recipients and reduced burden for carers.

### **9.2.2 Care coordination and case management interventions for specific types of carers and care recipients**

Studies to date have reported positive outcomes for carers of people with dementia, frail aged and stroke.

## **9.3 Counselling and psychosocial interventions**

### **9.3.1 General findings in relation to counselling and psychosocial interventions**

In total, 5 reviews and 4 studies of counselling and psychosocial interventions were reviewed. In addition, counselling and psychosocial interventions were reviewed as part of a number of multi-component interventions.

#### **Reviews**

Charlesworth (2001) reported that "the available evidence suggests that psychosocial interventions can be effective - especially those that are theory-based with a coherent and explicit rationale. However, there needs to be a much greater emphasis on targeting interventions according to specific characteristics of the carer and the person with dementia".

In contrast, Cooke et al. (2001) concluded that "overall, there is little evidence that interventions consistently produce benefits for caregivers in terms of improved caregiver psychological well-being or caregiver burden" (p129) and that "the efficacy of interventions is greater when caregivers' knowledge of illness is considered as an outcome" (p130).

Kneebone and Martin (2003) found that overall the research on coping in carers to people with dementia provides evidence that a general tendency to problem-solving and an acceptance style of coping is likely to be advantageous.

Low et al. (1999) reported that most intervention studies focusing on carers' psychological health and the negative impact of stroke showed mixed results but that a carers' ability to cope was enhanced by use of positive coping strategies and more stroke information (concrete approaches).

In a study of psychological treatments in schizophrenia, Pilling et al. (2002) found that family therapy had clear benefits.

Martire et al. (2004) in a RCT review of interventions involving a family member reported that there were positive effects for carer burden, depression and anxiety. The best results were for carers of people with non-dementing illnesses and interventions that only targeted the family member and addressed relationship issues. Statistically significant aggregate effects were generally small in magnitude. They suggested that improvements in family carer depressive symptoms and burden may have reduced the risk of carer mortality.

## Studies

### Well supported practice

Lavoie (2005) in a Canadian study of 30 family carers of people with dementia reported on a successful intervention consisting of 15 x 2 hour weekly sessions comprising cognitive appraisal and coping strategies. The authors attribute the results to the intensity of the intervention and the focus on coping strategies for dealing with their relatives' dysfunctional behaviours.

Schultz et al. (2006) in a US palliative care study found that reducing carer burden, treating depression before the death of the loved one, and providing supportive psychosocial or skills training carer interventions may help the carer better manage the sequelae of death.

### Carers' views

Yip (2003) reported that the use of guided imagery, role-playing, humour, and paradoxical intervention was successful with Chinese female carers in Hong Kong.

Venables et al. (2006) in a randomised controlled trial of a specialist clinical assessment (of care recipients) found that overall level of distress was significantly reduced and that distress was associated with 2 attributes of the care recipients: under-activity and the requirement for physical care. A change in the mood of the care recipient from baseline (depression) level was the only factor to significantly predict a change in carer distress. However, a serious limitation of this study is that the authors were unable to provide information on services delivered as a follow up to the clinical assessment report.

### 9.3.2 Counselling and psychosocial interventions for specific types of carers and care recipients

No studies were identified that provided clear evidence on the effectiveness of counselling and psychosocial interventions for different types of carers.

## 9.4 Respite care, including day centres

The best evidence from well controlled trials has long suggested that in spite of the levels of satisfaction reported and apparently obvious practical benefits, few positive effects on carer wellbeing can be directly attributed to the use of respite services. The reasons for this lack of clear evidence are discussed in the following sections.

### 9.4.1 General findings in relation to respite care

## Reviews

Since the early 1990s the discrepancy between experience and evidence around the efficacy of respite care has been discussed in the academic literature. "Recent momentum for increased provision of residential respite services for people with dementia is not supported by empirical data. Yet the literature is replete with anecdotal reports indicating the efficacy of residential respite. This discrepancy may have resulted from methodological flaws in the research, lack of awareness by consumers and health professionals and great diversity in the reasons for, and among the recipients of, respite. The prescription of respite care will need to be more specific and rigorous -

matching the correct dose of respite care to the needs of recipients and caregivers - for future research to demonstrate its efficacy.” (Brodaty and Gresham 1992, Abstract)

A later review by McNally et al. (1999) drew a similar conclusion finding that there was little evidence that respite intervention had either a consistent or enduring beneficial effect on carer well-being. They suggested that a more 'carer-centred' approach is required in both the provision and evaluation of respite care intervention. This approach would address the experiences of both carers and care-recipients during the respite period. As with other authors, they noted that the majority of the work conducted to date has been methodologically poor.

Gaugler and Zarit (2001) reported that an elderly client typically attends an adult day program for 2 or 3 days a week for about 5 hours a day. However, adult day care is not homogenous, nor does it serve a generic population. As such, they classified interventions as either 'medical' programs or 'social' programs. They found satisfaction with services and that family carers seem to benefit from utilising adult day services over time. However, adult day programs act more as a supplement to informal assistance than a substitute for nursing home care, and the functional status of clients is often not affected.

In a review of respite care in palliative care, Ingleton et al. (2003) reviewed 260 papers, of which 28 related directly to adult respite care in specialist palliative care. These were largely concerned with descriptive accounts of respite programs, guidance on referral criteria or evaluating effects on patients but not carers. They found no empirical studies evaluating the impact of respite care provided by specialist palliative care services on carer outcomes.

Lee and Cameron (2004) reviewed three RCTs that compared respite care with a control intervention for people with dementia. (Grant 2003: 60 hours in-home respite over 2 week period; Lawton 1989: 3 types of respite over one year period with some paying/subsidised/free; Wishart 2000: weekly visiting/walking program for people with dementia, 2.5 hours, for 6 weeks). They concluded that "Analysis of the data showed no significant effects on caregiver outcomes and there was no evaluable data for people with dementia" (p.7) but warned that "these results should be treated with caution, however, as they may reflect the lack of high quality research in this area rather than an actual lack of benefit." (p.1)

In a review of RCTs, Flint (2005) found that there is little evidence that respite care for a patient with dementia significantly affects carer burden or delays institutionalisation of the patient. However, many carers report "high levels of satisfaction with respite services". (p. 516)

An instrumental review in 2007 drew a similar conclusion. "This review provides some evidence that respite for caregivers of frail elderly people may have a small positive effect upon caregivers in terms of burden and mental or physical health. Caregivers were generally very satisfied with respite. No reliable evidence was found that respite care delays entry into residential care or adversely affects frail older people. Economic evidence suggests that day care is at least as costly as usual care." (Mason 2007a, p. 298) This finding is based on a comprehensive review that included a total of 10 RCTs, 7 quasi-experimental studies and 5 uncontrolled studies.

## Studies

### Well supported practice

An important RCT of respite care for carers of Alzheimer's patients was conducted by Lawton et al. in 1989. Half of the 642 participants received subsidised respite care in the context of ongoing case management, counselling, informational and educational services and half received only counselling and information at enrolment. Over 12 months, families with respite care maintained their impaired relative significantly longer in the community (22 days). Although respite was ineffective for carer burden and mental health, satisfaction was very high. Although not a strong intervention, respite care can increase carers' quality of life.

Kissane et al. (2006) reported on a randomised controlled trial using 257 families of patients dying from cancer (including a sample in Melbourne) who were assigned to family focused grief therapy or a control condition. The primary outcome measures used were the Brief Symptom Inventory, Beck Depression Inventory, and Social Adjustment Scale. The authors concluded "Family focused grief therapy has the potential to prevent pathological grief. Benefit is clear for intermediate and sullen families. Care is needed to avoid increasing conflict in hostile families." (p.1208)

### **Acceptable practice**

Gaugler et al. (2003) reported on adult day service use and reductions in caring hours for dementia carers and concluded that adult day service use is potentially effective in reducing carers' emotional and psychological distress.

Grant et al. (2003) reported on a two week respite intervention (random assigned) with follow-up testing one month post intervention. They concluded that "the study provides preliminary evidence that a simple respite intervention may be useful in reducing sympatho-adrenal-medullary arousal in a subgroup of carers who may be considered vulnerable to deleterious health outcomes by virtue of being placed under unusually burdensome caregiving circumstances in the context of inadequate social support." (p.70)

Holm and Ziguras (2003) reported on a small study of 18 care recipients who received host-home respite. The cost of providing host-home respite was almost 40% cheaper than in-home care, but both services cost more than centre-based care (day and overnight) because of the higher staff-client ratios. "The model may be particularly suitable for people of non-English-speaking background and for Aboriginal groups because it may allow more culturally sensitive options such as care workers from the same background, appropriate activities and culturally specific food. However, such models would need support from a larger organisation, perhaps an existing respite service, for staff support and training, financial management, central monitoring and accountability." (p.144)

In a study examining the effect of institutional respite care on sleep, Lee et al. (2007) found that the carers sleep benefited from respite. However "for caregivers...improved sleep quality during respite may come at the cost of personally disturbed sleep quality during the immediate post respite period...with improvements during respite period quickly returning to baseline in the immediate post respite period" (p. 257). They conclude that institutional respite offers the potential to improve quality of sleep and quality of life for dementia caregivers.

### **Carers' views**

In a community survey of children with severe intellectual disability and their families, Hoare et al. (1998) found that respite placement ranged from simply attendance at a children's centre, to year-round residential placement. Distress among carers was consistently associated with increased disability in the child. Respite use was found to be a valuable resource for many carers and its use is indicative of underlying distress in the carer.

In another study of parents caring for a child with a disability, Treneman et al. (1997) found that the child's level of dependency and the presence of behaviour and communication problems led to significantly higher levels of experienced stress among carers. This was also associated with a significantly greater use of respite care except by families of children with behavioural problems. The results showed that respite care was generally perceived as an inadequate service, though 88% of respondents had no knowledge of the existence of respite care services.

#### **9.4.2 Respite care for specific types of carers and care recipients**

No studies were identified that provided clear evidence on the effectiveness of respite or day care interventions for different types of carers.

## **9.5 Educational and psycho-educational interventions**

### **9.5.1 General findings in relation to educational and psycho-educational interventions**

#### **Reviews**

In a study on carers supporting people with intellectual disability and challenging behaviour, Allen (1999) reviewed the factors that may impact on effectiveness of behavioural interventions for people with ID and challenging behaviour, including carer attitudes and beliefs, carer emotional responses. It was found that interventions based on a functional analysis of target behaviour are generally likely to produce superior outcomes and that behavioural interventions with the client could be enhanced by utilising additional psychological approaches with carers.

Hassiotis and Hall (2004) reviewed 3 RCTs on behavioural and cognitive-behavioural interventions for outwardly-directed aggressive behaviour in people with learning disabilities. The treatments varied between studies (i.e. anger management based on modified relaxation, social skills training based on behavioural techniques, problem solving and assertiveness training and anger management using cognitive-behavioural principles). The results suggest that both carers and participants found anger management beneficial after 9 weeks training and continued to do better after 3 month follow-up.

In a review of strategies to enhance the problem-solving skills of family carers of stroke patients, Lui et al. (2005) found that few studies examine variables associated with carer problem-solving abilities. Interventions included specialist nurse visits, telephone social problem-solving and psychosocial interventions. Teaching effective problem solving skills was reported to be useful in enhancing carer problem-solving abilities and reducing depression but most studies did not describe the details of the intervention or give sufficient evidence to support the reported findings.

Smith (2004) reported on the Progressively Lowered Stress Threshold (PLST) model and concluded that the PLST model decreases depression, diminishes uncertainty and unpredictability associated with dementia caring, lessens carer appraisals of stress and burden while promoting levels of satisfaction, and reduces carer reactions to behavioural symptoms. Key elements of PLST are ongoing education; assistance with development of routines and strategies that enhance behaviour; help in simplification of day to day care tasks; assistance with problem-solving strategies, locating community resources and developing social networks, ongoing emotional support and counselling and case management.

#### **Studies**

##### **Well supported practice**

Castro et al. (2002) reported on a trial in which women caring for relatives with dementia were assigned to either a 12-month moderate-intensity home-based exercise training program or a 12-month attention control (nutrition education) program. This RCT found that exercise and counselling can successfully encourage a stressed and burdened population to engage in physical activity at levels sufficient to produce health benefits. Both groups significantly improved in perceived stress, burden, and depression from baseline to post-test. Women who were older, less depressed, and more anxious at baseline showed better retention, and lower baseline depression was associated with better exercise retention.

Female carers aged 50 and over caring for a relative with dementia were assigned to either anger management or depression (small group-class) interventions, or to a wait list in a study reported by Coon et al. (2003). They reported that carers respond well to time-limited, group-based psycho-educational and skill training interventions grounded in cognitive behavioural principles with reductions in symptoms of anger, hostility, and depression as well as increases in self-efficacy for managing behaviour problems and controlling upsetting thoughts in both groups.

Gitlin et al. (2003) reported on a US RCT of 255 families, with 190 follow-up interviews as part of an Environmental Skill-building Program (ESP). The intervention group received 5 home contacts and one telephone contact by an OT who provided education, problem-solving training and adaptive equipment; 6month follow-up. They found that the difficulties carers confront are multi-faceted, that ESP had multiple but selective benefits. It did not result in improvements uniformly across all hypothesised outcomes. They suggested that this type of intervention should be integrated into home and community based services for families.

Huang et al. (2003) piloted a home-based training program for improving carer self-efficacy and decreasing the behavioural problems of care recipients with dementia in Taiwan. The 24 carers in the experimental group received a two-session in-home training program (separated by 1 week, with visits lasting 2-3 hours) with follow-up telephone calls and the 24 in the control group received only written educational materials with general information about dementia. The program focused on nurse-carer collaboration, with individualised training. They reported that the experimental group displayed significantly decreased behavioural problems in the person with dementia (except for physically aggressive behavioural problems), and also increased self-efficacy of the family carers.

In an Australian RCT of a psycho-educational intervention for family carers of patients receiving palliative care reported by Hudson et al. (2005), participants (n=106) received standardised home-based palliative care services (n=52) or these services plus the intervention (n=54). The nurse-delivered intervention consisted of 2 home visits supplemented by a follow-up phone call between the 2 visits. A carer guidebook (written information related to typical aspects of caring for a dying person) and audiotape (featuring reflections from carers and incorporating self-help strategies and relaxation exercise) were used to complement the nurse interactions. No intervention effects were identified with respect to preparedness to care, self-efficacy, competence, and anxiety. However, participants who received the intervention reported a significantly more positive carer experience than those who received standard care. The authors conclude that it is possible to increase carer rewards despite being immersed in challenging circumstances that often yield considerable negative psychosocial sequelae.

### **Supported practice**

Ducharme et al. (2006) reported on a stress management intervention for family carers of elderly relatives living at home. The intervention involved 5 weekly visits by case-manager and one follow-up meeting. They reported significant positive effects on perceived challenges associated with caring and improvements in areas such as use of social support, use of problem-solving, seeking and accepting help, relationships, self-care and empowerment. But no significant effects were found for burden, perceived distress or health.

### **Acceptable practice**

An intervention aimed to equip carers with simple massage skills that they could use at home with their children with disabilities was reported by Cullen and Barlow (2004). They found statistically significant improvements in carers' self-efficacy in their ability to conduct massage, in managing children's psychosocial wellbeing and in levels of anxious mood. Carer reports of children's sleeping patterns and eating also showed significant improvements.

Dicker et al. (2005) reported on a training project for the management of behaviour and psychological symptoms of dementia (BPSD) by home-based carers. Education modules were delivered one-to-one in the carers' homes by community-based mental health professionals. Training times ranged from four to ten weekly or fortnightly sessions lasting 30-60 minutes. The package of nine modules provided practical strategies for managing 25 of the most common behavioural and psychological symptoms of dementia. Carers made statistically significant learning gains and gained in self-perceived knowledge of dementia and its behavioural and psychological symptoms, management of these symptoms, care-giving ability and confidence, and

stress reduction. These gains were maintained six months and 12 months after training, with the exception of stress, which had returned to near pre-intervention levels by 12 months.

### Emerging practice

A study on linking primary care physicians with community-based dementia care services, Fortinsky (2002) involved 29 physicians and 62 family carers over a 6 month period. A service coordinator established an individualised plan for the carers on all non-medical aspects of dementia care and available resources in the community, with monthly follow-ups for 6 months to see what actions had been accomplished and what barriers there were, if any. The plan was also forwarded to the family physician so they could participate in/monitor action plan. Despite the relatively small sample size (44 in the evaluation), they found statistically significant increases in reported levels of dementia symptom management self-efficacy, and in community support service self-efficacy.

Levesque et al. (2002) tested a group intervention model to improve carers' ability to cope with stress. It involved active modelling strategies, role-playing, homework and exercises during meetings. They concluded that the intervention prompted carers to examine the meaning that they give to their caring experience, to question themselves and to examine their values, beliefs and thoughts, which may hinder their efforts to cope with the difficult aspects of their role.

Tait and Cutler (2005) also tested group therapy, this time with carers of people with communication impairments. One hour sessions once a week for 4 weeks, was delivered by speech pathologists. Themes included communication, emotional issues, lifestyle, role change and identity, information and access to services. The group provided the opportunity for therapists to suggest practical speech therapy solutions, support, education and training and to change in focus from communication deficits to positive capabilities of the patient in communication and broader contexts. The authors noted the importance of wider multidisciplinary involvement, e.g. social worker.

Van Ast and Larson (2007) investigated the potential of telehealth to support rural carers. This Australian study of 8 rural carers involved six service providers and a videoconference program facilitator. A program of education and support was delivered to rural carers via teleconferencing. Carers reported having a positive interaction with the facilitator and other participants despite being at a distance, and the facilitator found the technology offered her more ways to observe non-verbal cues discretely. Carers retained the information provided and that they had made small behaviour changes. Video conference sessions were 16% and 47% of the cost of a face-to-face session. The critical element of this program was that local services were augmented and enhanced through the use of a facilitator who brought skills that were not available locally.'

### Carer views

Bloomberg et al. (2003) reported on a small study in Victoria, Australia involving 16 carers of 8 individuals, with carers working in pairs. Each pair comprised a carer from the individual's day setting and the other from the individual's home. Six training modules (days) were held once a month. Between monthly training sessions, carers completed work assignments and had 1 or 2 supervisory visits from course leaders. The project led to positive outcomes in terms of carers' knowledge of communication and that of the individuals, ability to be involved in goal-setting and intervention and to structure the social environment to increase communication opportunities. Poor outcomes included the failure of carers to complete tasks (mainly evaluative tasks) and to significantly impact on the individuals' physical environment.

An Occupational Therapy intervention was reported by Graff et al. (2006). Carers of people with dementia attended a series of 10 sessions over 5 weeks. They concluded that OT interventions might be of great value, because of the problems in daily performance and the decrease in the quality of life that dementia causes both for patients and their carers.

Care recipients with severe mental illness were asked about interventions to increase informal support networks and practical help plus informal caring in a study by Green et al. (2002). They reported relying heavily on only one or two key informal carers, and often needed significant support from mental health professionals. The limited numbers of carers and social isolation placed them at risk of negative outcomes if informal support resources were to be lost.

An Australian education program for rural carers of people with a mental illness was reported by Hayman (2005). The Carers Education Exchange Program is a flexible, needs based model that can be modified to cater for individual groups. The program has an educational format, conducted in a supportive setting that encourages development of mutual support among carers. The feedback from carers indicated that the program has substantial (short-term) benefits for carers, particularly in increasing their knowledge and understanding, and reducing some of the negative emotions associated with mental illness and the stigma surrounding it. It also served to reduce the isolation experienced by many rural carers.

### **9.5.2 Educational and psycho-educational interventions for specific types of carers and care recipients**

Some of the studies described above show promise for rural carers. About half of the papers on educational interventions have targeted carers of people with dementia, with most of the others targeting mental illness and disability.

## **9.6 Family support interventions**

### **9.6.1 General findings in relation to family support interventions**

#### **Reviews**

Four reviews of family support interventions were synthesised. All focused on mental health clients and their carers/family. Cuijpers (1999) reviewed family interventions with families of people with schizophrenia. They reported that the length of the family intervention is the key to interventions' effectiveness on carer burden. Long-term interventions with 12 sessions or more are effective, less than 10 sessions had little effect.

In a review of RCTs of crisis intervention models versus standard care for people with severe mental illnesses, Joy et al. (2004) found that crisis/home care reduced family burden and was a more satisfactory form of care for both patients and families.

Pharoah et al. (2006) reviewed 43 studies. Family interventions were reported as having good outcomes for patients and may improve general social impairment and the levels of expressed emotion within the family. However, no outcomes were measured for family or carers.

Pitschel-Walz et al. (2001) investigated the effect of including relatives in schizophrenia treatment. The studies investigated family intervention programs to educate relatives and help them cope better with the patient's illness. The main result was that the relapse rate can be reduced by 20% if relatives of schizophrenia patients are included in the treatment. If family interventions continued for longer than 3 months, the effect was particularly marked. Furthermore, different types of comprehensive family interventions have similar results. The bifocal approach, which offers psychosocial support to relatives and schizophrenia patients in addition to medical treatment, was clearly superior to the medication-only standard treatment. The effects of family interventions and comprehensive patient interventions were comparable, but the combination did not yield significantly better results than did a treatment approach, which focused on either the patient or the family.

## Studies

### Well supported practice

A study on a nurse interventionist, who role-modelled and coached carers, problem-solved and helped them make connections between context and behaviour as reported by Mahoney et al. (2006). In-home visits assistance with personal care e.g. hygiene were also provided. Five key lessons were reported: (a) identification of caring dyads before crisis must be improved; (b) real-time observation is essential to develop individualized interventions targeting behavioural aetiologies and developing carer skills and efficacy; (c) intervention delivery depends on the skills of the nurse; (d) complex carer situations, such as competing demands, stress, health, and past experiences or family relationships, affect treatment receipt and enactment; and (e) intervention enactment requires coaching practice and support over time.

A Dutch RCT of 122 people with dementia with 58 pairs receiving emotional and practical support (4 hours per week for 10 months) aimed to investigate predictors of change in sense of competence and admission to residential care. Vernooij-Dassen et al. (1997) found that, while carer characteristics do not influence the risk for institutionalisation, "attention can be given to the negative consequences of agitated behaviour by giving the primary caregiver the opportunity to express feelings caused by the agitated behaviour and by explaining its nature. Attention should be given to the most vulnerable group, females living with the demented patient. These females were found to be sensitive to our intervention. The supportive predictors indicate the importance of both emotional and practical support and of supportive skills." (p.675-6)

### Economic evaluation

In a study exploring patterns and correlates of service use, need, and knowledge among older mothers of adults with mental disabilities, Smith (1997) found that overall service use was low despite high knowledge. Also, the number of services needed exceeded number of services actually used. Greater service use occurred when offspring were younger, female, from lower income households and were receiving high levels of care from mothers who reported higher subjective burden and self-reported health. Families had larger unmet service needs when mothers were married, received less assistance from their children without mental retardation, and reported higher levels of subjective burden.

### Carers' views

In a study exploring stress in UK families conducting intensive home-based behavioural intervention for their young child with autism, Hastings et al. (2001) found that adaptive coping strategies, informal social support sources, and beliefs about the efficacy of the intervention were associated with lower reported stress and higher levels of autism symptomatology were associated with higher reported stress. There was also evidence that the use of Passive Appraisal coping and beliefs about the efficacy of the interventions moderated the effects of autism symptomatology on parents' pessimism.

Kumamoto et al. (2006) examined usage of home care services among family carers of disabled elderly in Japan. The results revealed that use of home care services was associated with lower feelings of burden among family carers. The authors also reported that ADL deficits and severity of dementia of disabled elderly are related to higher burden and that the availability of instrumental support from other family members was associated with lower burden. The results also suggest that service use affects the relation of severity to burden and may mediate the impact. Taken together, the findings suggest that carers of people with more severe impairment used more services which resulted in lower burden.

This Japanese study used a translation of the Zarit burden tool and is one of the few examples of a study examining 'dose effects' in this case in terms of the hours of home care used. According

to the authors, "...this is the first observational (cross-sectional study) to clearly show the effect of the use of care services on the reduction of caregiver burden in a community setting." (p.169)

### **9.6.2 Family support interventions for specific types of carers and care recipients**

All of the reviews of family support services targeted carers of people with a mental illness. The evidence is also good for carers of people with dementia, with four well designed studies finding that family support is effective.

## **9.7 Support groups**

### **9.7.1 General findings in relation to support groups**

#### **Studies**

##### **Well supported practice**

A RCT involving 96 Chinese families caring for a relative with schizophrenia in Hong Kong was reported by Chien et al. (2005). 12-session mutual support groups (n = 32) were compared with a psycho-educational group (n = 33) and standard care (routine family support service group, n = 31). Family carers and patients in the mutual support group reported statistically significant improvements on family and patients' level of functioning, when compared with their counterparts in the psycho-education and standard care groups. The authors suggest that mutual support groups are an effective modality of family intervention in a Chinese population caring for a family member with schizophrenia to improve both family and patient functioning.

##### **Supported practice**

Harding et al. (2004) evaluated a short-term group intervention for informal carers of patients attending a home palliative care service in London. The intervention group of 36 carers was compared with a comparison group of 37 carers and analyses included examination of differences between employed and not employed carers. While the quantitative data showed no psychological benefits, the qualitative data indicated that carers had derived some benefits from the sessions. One explanation for this contradiction could be the timing of the post-intervention measure. At this time, carers have to adapt to the loss of group support. If psychological measures were taken during the life of the group instead of after it ceases, the results may be different.

##### **Acceptable practice**

Kaasalainen et al. (2000) reported on a convenience sample of 23 female carers for an elderly relative, registered to attend the Caring for Aging Relatives (CARG) program in Canada. These were matched with a comparison group of 23 female carers in the same community, not attending CARG, on age, length of caring and relationship to care recipient. Information and support was provided to carers in small groups in a community setting. Groups ran for one 2-hour session per week over 8 weeks and were delivered by public health nurses. Comparisons between the control and intervention groups are flawed because of poor matching of groups. Those who took part in CARG had high scores for morale, social support and information at both onset and end.

##### **Emerging practice**

Harding et al. (2002) reported on a multi-professional short-term group intervention for informal carers of patients using a home palliative care service. The intervention aimed to overcome the ambivalence of people who were unwilling to identify themselves as carers or discuss their needs. The overall theme of the '90-Minute Group' was 'Caring for Ourselves'. A maximum of 12 carers attended six weekly closed sessions of 90 minutes duration. "Qualitative data from attendees showed that identifying with other carers and validating feelings, asking questions of professionals,

and providing each other with support and encouragement were valuable outcomes from the group." (p. 275)

The Circle Model was reported in a study by Jansson et al. (1998) on relatives of people with dementia. The intervention consisted of 5 weekly sessions for 3 hours each. Participants (both carers and volunteers) were reported to be satisfied with the model and the authors concluded that "the circle model brings new dimensions to the home care services... (and) should serve as a complement to social services support." (p. 681)

An Australian study by Shanley et al. (2004) investigated the use of the telephone for running carer support groups for family carers of people with dementia. The program focused on people from CALD or Indigenous backgrounds and people in rural areas. 10 groups were conducted in Greek, Cantonese, Korean and Italian, English-speaking carers in rural areas and one group for Aboriginal carers. Each group consisted of 4-6 carers and ran once a week for 60-90 minutes for between 5 and 8 weeks. Overall, participants felt very strongly that their involvement was worthwhile. The main benefit was being able to obtain support and information from each other. The anonymity of the teleconference format appealed to a number of participants. Recruitment, especially in smaller CALD communities, and translation of materials was time consuming. CALD participants gained similar benefits to English-speaking participants. However, the content and format was not always culturally appropriate for Aboriginal people. The authors concluded that telephone support groups can be useful for carers who are isolated or housebound and appear acceptable to people from CALD backgrounds, although possibly not for Aboriginal people.

### **Carers' views**

McGuire et al. (2004) reported on a psychosocial occupational therapy intervention program designed to increase the satisfaction, time use, and occupational performance (and well-being generally) of mothers with school-aged children with disabilities. It involved 6 weekly group sessions and an individual session at beginning and end. The authors concluded that such support groups can importantly contribute to mothers' well-being.

A Carer and Depression Support group (CADS) was reported by Smith (2006). Running in an Australian rural town, carers attend an informal community, consumer developed mixed support group for depression. The group includes people with depression, carers/parents and professionals. Interactive sessions are led by volunteer professionals with assistance by consumer participants. Meetings are held twice a month, alternating mornings and evenings for maximum accessibility. Anecdotal feedback is that participants positively value the group.

### **9.7.2 Support groups for specific types of carers and care recipients**

The number of well designed studies of support groups is limited. However, there is emerging evidence that support groups may be appropriate for carers of CALD backgrounds, carers of children with disabilities and carers of people with mental illness.

### **9.8 Multi-component interventions**

Twenty reviews of multi-component interventions were identified. The best of these are summarised below.

#### **Cancer/palliative care**

Harding and Higginson (2003) reported on a systematic literature investigating is the best ways to help carers in cancer and palliative care. Interventions included home nursing, respite, social networks and activity enhancement, problem solving and education and group work. They concluded that the evidence contributes more to understanding feasibility and acceptability than to effectiveness. Carers report high satisfaction with home care services (nursing or hospice) but users still have high levels of psychological morbidity and unmet need. Similarly, carers are

satisfied with respite care in the form of 'sitting services' provided by professionals or volunteers. High quality evaluation data are lacking for either of these interventions. An 'activation program' was effective in increasing carers' social activity in the last few months of the patients' lives. One-to-one psychoeducational interventions have been rigorously evaluated, but findings are mixed. Carers groups have been shown to increase knowledge but not necessarily improve psychosocial adjustment.

## Dementia

Pinquart and Sörenson (2006) reported that interventions with carers for patients with dementia have, on average, small but meaningful effects on reducing burden and depressive symptoms, and increasing ability/knowledge and SWB (subjective well-being) and, for a subset of interventions, reducing the risk of institutionalisation. They noted that research is needed regarding how the complexity of interventions relates to treatment effects and which combinations have the largest effects.

Schultz et al. (2002) agreed, concluding that there is evidence of clinically significant outcomes in the carer intervention literature. "Interventions show promise of achieving clinically significant outcomes in improving depressive symptoms, and, to a lesser degree, in reducing anxiety, anger and hostility...(and) some impressive and clinically meaningful effects have been demonstrated for delayed institutionalization of the care recipient" (p598). "There exists strong consensus that all caregivers are likely to benefit from enhanced knowledge about the disease, the caregiving role, and resources available ... caregivers might additionally benefit from training in general problem-solving skills, as well as from interventions that target managing care recipient behaviours or caregivers' own emotional response to caregiving." (p599)

In contrast, Pusey and Richards (2001) undertook a systematic review of studies using technology based interventions (computer network providing carers with education, decision, support and communication and telephone support) plus both group and individualised interventions. They concluded that there is no evidence to support the use of psychosocial interventions that utilise technology, nor is strong evidence of their ineffectiveness. They also reported that the evidence for both group and individual interventions is fairly weak. The 'strongest' case is for individualised interventions, particularly counselling and psychosocial interventions.

Patterson and Grant (2003) explored physical outcomes for carers in dementia and interventions to reduce negative health consequences. They concluded that intervention studies designed to reduce distress have shown modest success, but have largely ignored physiological outcomes. They note the need to recognise the positive aspects of caring, "Interventions designed to reduce the stress of caregiving have mixed this segment of the population with more vulnerable caregivers (which) may be why the effects of these interventions have been relatively modest." (p632)

The body of work built up by Brodaty and his colleagues (Brodaty et al. 1989, 1992, 1994 and 1997) in the area of dementia caregivers' training programs, combined with respite, is impressive in its methodological rigour and the implications it has for service provision for carers (diverting resources from residential care budgets to caregivers training programs). The effects of their 10 day training and education programme, which were to reduce stress in carers and delay institutionalisation has been demonstrated through a quasi-experimental evaluation. The benefits for the caregiver and the patient were greatest when the interventions were introduced early in the course of dementia. "The challenge is to develop specific indications and contraindications for psychosocial interventions so that these can be prescribed accurately." (Brodaty et al. 1997, p191).

Kennet et al. (2000) sums up much of the literature in concluding that anyone expecting to find a silver bullet solution to alleviating carer distress will clearly be disappointed. "There is no single, easily implemented and consistently effective method for eliminating the stresses of caregiving" (p79). But that there exists strong consensus among researchers that all carers are likely to

benefit from enhanced knowledge about the disease, the caring role, and resources available to carers. Once information needs have been met, the carer may benefit from additional interventions (general problem solving skills, simultaneously treating the care recipient, altering the social and physical environment of the carer/care recipient dyad). They conclude that the literature clearly points to one overriding finding, namely that interventions which are “comprehensive, intensive, and individually tailored are likely to be more effective than those that are not.” (p. 79)

### **Frail aged**

A major review by Sørensen et al. (2002) found good evidence of the effectiveness of multi-component carer interventions. Taken together, all carer interventions produced a significant improvement (between 0.14 and 0.41 SD units) in carer burden, depression, subjective well-being, satisfaction, ability/knowledge and care receiver competence. Psychoeducation and psychotherapy had a significant effect on all outcome variables. Multicomponent interventions had significant effects on burden, well-being and knowledge. Respite was effective for reducing burden and depression and enhancing well-being. Individual interventions had stronger effects on burden and wellbeing, while group-based interventions had larger effects on care receiver competence. (It should be noted that social support outcomes were not included in the meta-analysis). People caring for a dementia patient were less likely than others to benefit from interventions. Studies with a higher proportion of spouse carers (*vis-à-vis* adult children) tended to find smaller improvements in burden, depression etc but greater improvements for care receiver symptoms.

Yin et al. (2002) drew similar conclusions. The weighted mean effect size for group intervention studies was 0.41 (95% CI 0.32-0.51) indicating a moderate, positive treatment effect on carer burden. Effect sizes varied widely between studies, particularly among the quasi-experimental studies (which tended also to report larger effects than the controlled studies). For the individual interventions, the weighted mean effect size was 0.48 (95% CI 0.30-0.67). This was reasonably homogeneous (that is, the studies reported similar sized effects). This type of intervention mainly consisted of psychosocial counselling.

Farran (2001) provides an overview of the key research themes in the carer intervention literature from 1980 to 2000 with a particular focus on psychosocial interventions. The overall finding is that carers benefit from information, support from others, assistance in learning more about specific caring skills, and encouragement for maintaining a program of self-care.

Finally, Stoltz et al. (2004) make the point that most studies interweave why family carers are in need of support as well as how to support them and that the two do not always match. It “appears that care and services are ‘given’ to family carers, rather than being negotiated and individually tailored to their needs... It seems as the professionals’ view on support is dominant in service provision, family carers may have another point of view regarding what constitutes support for them.” (p.117)

### **Stroke and brain injury**

Bhogal et al. (2003) investigated community reintegration after stroke with outcome measures for both patients and carers. Psychological morbidity in carers was found to be associated with stroke severity, the carers’ health, low socioeconomic status, the amount of time required to care for the stroke patient, the patient’s behaviour and mood, younger stroke patients and a smaller social network. Older, healthier carers with higher incomes were less likely to suffer depression and psychological strain. They found that family education had positive benefit if it involves active educational-counselling.

Boschen et al. (2007) looked at the evidence from RCTs for family interventions after acquired brain injury and other chronic conditions. They found no strong research evidence supporting any specific intervention method for family carers of individuals with ABI (Acquired Brain Injury) or any

of the other [similar] chronic condition groups surveyed, although an abundance of anecdotal descriptive and quasi-experimental support exists in the rehabilitation literature.

In a study of the effectiveness of information provision, Forster et al. (2007) concluded that the 'effectiveness' of information provision has not been conclusively demonstrated. However, information combined with education sessions improved knowledge and was more effective than simple provision of a booklet or leaflet. There is little evidence of an association between information and education provision and emotional outcomes.

Lee et al. (2007) reported on the evidence in relation to education/skills training, family support/functioning, psychosocial and support groups. They reported that interventions were effective in improving the mental health of informal carers. Effect and quality ratings of educational program interventions were larger than support programs. Education programs used more focused content. Goals of support programs may have been too broad. Effect size for a-theoretical intervention studies was larger than for theory-based studies; had larger sample sizes and therefore carried more weight in the analysis.

Sinnakaruppan and Williams (2001) investigated case management programs for head injury and family carers. These programs varied from behavioural to cognitive interventions to help carers adjust to particular problem behaviours in their injured relatives. Most were poorly evaluated but one study found a statistically significant difference in the use of supportive coping techniques following the support program.

Visser-Meily et al. (2005) reported on intervention studies for carers of stroke survivors. The four main intervention approaches were providing specialist services, (psycho) education, counselling, and peer social support. Ten studies reported significant on one or more outcome measures. For counselling, 3 out of 4 studies showed a positive overall effect, even up to 3 years after stroke, in terms of increased confidence in knowledge about patient care and increased use of active coping strategies. They found that early discharge from hospital had negative effects for carers, even when supported. They concluded that they could not identify specific interventions that were clearly beneficial for carers because of the variety of measures used but that it seems difficult to change strain, wellbeing or emotional status of carers in a positive way.

## Studies

### Well supported practice

Gitlin et al. (2003) reported on a multi-component intervention on burden and depression among carers of people with dementia. There were 15 interventions across 6 sites including skills training, telephone-linked computer support, environmental skill building program; behaviour and enhanced care; family based multi-system in-home intervention; coping with caring and enhanced support groups and information and referral. They concluded that there is no single, easily implemented, and consistently effective method for eliminating the multiple stresses of providing care to people with dementia. A multi-component intervention that includes elements that target different aspects of the carer's experience (e.g., affective responses, behavioural burden, and unsafe physical environment) might be most beneficial.

The results for dementia carers reported by Brodaty et al. (1997) are similar to those described above and were based on a prospective, randomised control trial and longitudinal follow-up over approximately 8 years. There were ten components to their training and educational program, as well as a 10 day respite component for one of the groups while the patient received a live-in memory retraining intervention. The content of the program covered: reducing distress; combating isolation; guilt and separation; new ways of thinking; new coping skills; fitness, diet and organising the day and home; medical aspects of dementia; using community services; planning for the future; and coping with problem behaviours.

In a RCT, Quayhagen et al. (2002) evaluated four interventions (cognitive stimulation - 1 hour for 5 days per week; dyadic counselling - marital/couples therapy including both dyads; dual supportive seminar groups - 7 sessions group work; early-stage day care - respite and education/training for carers) for carers of people with dementia. They concluded that, although carer comments support the validity of these interventions, more definitive quantitative findings to support the differentiation of group potential would have been helpful.

Yaffe et al. (2002) reported on a RCT study in which in-home and community based services and case management were provided to people with dementia and their carers over a 2 year period. They found that patient and carer characteristics together predicts long-term care placement better than consideration of either patient or carer characteristics alone. "Some of the patient and caregiver variables that were associated with risk of nursing home placement, such as patient's living status, level of functional and cognitive impairment, and caregiver age, are not readily amenable to interventions... A comprehensive support and counselling intervention for spouse-caregivers of patients with Alzheimer disease reduced time to nursing home placement by nearly 1 year compared with those not receiving the intervention." (p. 2096)

### Acceptable practice

In a study on dementia (Bedard et al. 1997), participants and carers underwent a standardised baseline assessment, and carers were provided with education about dementia and interventions to reduce burden. Interventions potentially included a change in medication regimen, respite care and support groups. Follow-up visits occurred (1-12 months), where patient's condition and carer burden re-evaluated. They found that male carers were more likely to report reductions in burden than female carers. They also found that dysfunctional behaviours and carer burden are highly variable within individuals. "Whereas some patients and caregivers may benefit from our intervention, the situation in others may deteriorate sufficiently to negate any beneficial effects of the intervention." (pp. 285-6)

Gitlin et al. (2006) reported on a multi-component intervention consisting of adult day services as well as a care plan, education, counselling etc and emotional support for an average of one hour per month. They concluded that combining carer care management with adult day services results in clinically significant benefits.

In a study on the role of community mental health teams with people with dementia (Hoskins et al. 2005), nurses and social workers undertook joint assessment and care coordination and arranged access to respite, carers support groups and domiciliary assistance. They concluded that these interventions were significant in reducing carer stress. They stressed the importance of joint needs assessment in providing the correct and most appropriate interventions and argued that the importance of respite care was reinforced by the results of the study.

### Emerging practice

In a study of environmental strategies that were used by 100 family carers of people with dementia reported by Corcoran and Gitlin (2001), Occupational Therapists provided 5 x 90 minute home visits to generate environment-based solutions such as de-cluttering, installing grab bars and hand rails. Carers were willing to try a total of 1,068 strategies, of which 81% were subsequently used independently.

Friedman et al. (2006) reported on carers of frail older people in the Program of All-Inclusive Care for the Elderly (PACE), a community based system of preventative, primary, acute, and long-term care that cares for dual eligible (Medicare and Medicaid) US adults who qualify for nursing home care. PACE provides extensive formal services, including day care, home care, and meals. Carers are provided with education, provision of formal care that reduces burden short (e.g. day centre) and long respite care. The outcome measure was time from enrolment onto PACE to a long-term nursing home admission (i.e., >30 days). "Once participants were enrolled in PACE, the presence of a caregiver was not associated with the hazard of admission to a nursing home... One possible

explanation is that PACE is able to tailor formal services to compensate for the presence or absence of informal care.” (p. 462)

### 9.9 Summary of the evidence for specific types of carers and specific types of care recipients

As can be seen in Table 6, very few studies undertaken have a focus on specific groups of carers.

**Table 6 Evidence on needs and interventions according to carer groups**

Type of carer	Needs (No. of papers)	Interventions (No. of papers)
Parents of children with a disability	8	5
Male versus female carers	6	3
Aboriginal and Torres Strait Islanders	1	0
Culturally and linguistically diverse	4	0
Employed carers	7	0
<b>Total</b>	<b>26</b>	<b>8</b>

In terms of target groups, there is little evidence that the needs of carers systematically vary based on the type of person they are caring for. For example, there is little evidence to suggest that the needs of carers of people with dementia are different to the needs of carers of people after stroke. In both cases, the specific needs of the care recipient and attributes such as challenging behaviours do have an impact on the carer.

Interventions with carers of people with dementia have been the subject of the most research and, not surprisingly, the evidence is therefore strongest for this group.

Research into effective interventions for carers of the ‘frail aged’ is surprisingly sparse. For example, we could find no intervention papers on ‘co-dependent’ carers (e.g., elderly couples who are each others carer and care recipient).

While there is some survey data on employed carers, no studies were found that specifically addressed how best to address their needs. Nor is there much evidence on the impact of different payment arrangements for carer support services (e.g., free, co-payments, vouchers).

There is also little evidence on what interventions are most effective for carers in different types of relationships with the care recipient - parents, spouses, children, friends, resident and non resident carers. However, there is evidence to suggest that the same interventions achieve different outcomes for different carers. For example, Sörenson et al. (2002) found that spousal carers benefit less than adult children and that carers of people with dementia benefit less than other carers.

There is some evidence regarding the impact of gender differences in carers. Pinquart and Sörenson (2006) conducted a meta-analysis of 229 studies published between 1983 and 2005, and looked at the significance of gender differences in carer stressors, social resources, psychological health, and physical health. They concluded that “caregiving increases gender differences in depression and physical health, primarily because women experience more caregiving stressors” (p.39), however, women and men did not differ in their use of informal and formal support.

Only one study was found that focused on indigenous carers (McGrath et al. 2006). This was a study of the need for carer services for palliative care patients, rather than the effectiveness of such services. Lack of local respite services was documented to be negatively impacting upon the ability of carers to fulfil their caring duties and was found placing undue physical, emotional and economic stress upon carers, patients and their families. Lack of access to local respite services was found to be forcing rural and regional patients to relocate to metropolitan areas away from

family, community and land to which strong ties are held. Also lack of respite services was found to obstruct patients' and carers' wishes for death to occur in the local community.

Several studies have been reported on carer interventions for specific cultural groups. But no studies were found comparing the needs of carers from different cultures or the effectiveness of interventions across different cultural groups.

As the summaries in the attachments illustrate, the evidence synthesised for this review has implications for service provision. Equally, the gaps in current knowledge provide the platform for the development of a future research agenda designed to provide answers to some critical questions:

***Which carers?***

***Should receive what services?***

***From whom?***

***At what expected cost?***

***With what expected effect?***

## PART THREE STAKEHOLDER FEEDBACK ON THE EVIDENCE

The draft report was released in September 2007 to inform a national workshop of policy makers, academics, service providers and carer representatives. The workshop brought together these experts to review the findings of the report and to identify:

1. Priorities for improving routine practice in carer support networks
2. Priorities for building a coherent research and development agenda

### 10 National workshop

A total of 58 delegates attended the workshop at the University of Wollongong's Sydney Business School on 31 October 2007. A list of delegates is provided in Appendix Two.

Ms Mary McDonald, Assistant Secretary, Community Care Branch, on behalf of the Department of Health and Ageing, opened and closed the day's deliberations. Professor Kathy Eagar presented the findings of the review and invited workshop participants to comment. This resulted in a lively plenary session, in which delegates responded to issues as they arose from the presentation of the findings and engaged in debates around those issues. These discussions were continued into the afternoon's breakout sessions and recorded by the CHSD team along the way.

Overall, the findings of the review were accepted by workshop delegates. These findings, along with delegates' comments, are summarised in Section 10.1. Some specific questions were raised, particularly around the emphases and interpretations that should be given to the content of the final report. The writing team's attention was drawn to a number of additional articles and reports that could be usefully incorporated within this final report.

These emphases, themes and additions are summarised in Section 10.2. This part of the report concludes with some comments about the need for standard assessment and outcome measurement tools for carers, key issues that were raised by the literature review and became a recurring theme at the workshop (Section 10.3).

#### 10.1 *The evidence on supporting carers: literature review findings*

The literature review drew attention to a number of promising types of interventions, including:

- Case management and care coordination
- Counselling and psychosocial interventions, especially delivered individually
- Family support, especially for carers of people with mental illness or dementia
- Multi-component interventions

The literature review also highlighted many gaps in our knowledge of how best to support carers. There is strong demand for respite care, yet little research evidence that it has enduring benefits on carers' wellbeing or that it delays entry of the care recipient into residential care. Because this is a key service currently provided to Australian carers, the interpretation of this finding and recommendations for exploring the effectiveness of respite care requires very careful examination.

The workshop was informed that the issue of a lack of hard evidence for positive impacts of respite care was recognised as early as 1991 in a paper with the apt title "*Prescribing residential respite care for dementia - effects, side-effects, indications and dosage.*" This paper made the point that:

*"Recent momentum for increased provision of residential respite services for people with dementia is not supported by empirical data. Yet the literature is replete with anecdotal reports indicating the efficacy of*

*residential respite. This discrepancy may have resulted from methodological flaws in the research, lack of awareness by consumers and health professionals and great diversity in the reasons for, and among the recipients of, respite. The prescription of respite care will need to be more specific and rigorous - matching the correct dose of respite care to the needs of recipients and caregivers - for future research to demonstrate its efficacy.” (Brodaty and Gresham 1992, Abstract)*

Fifteen years later, it is still the case that little is known about the effective ‘dose’ of carer support interventions or when the best time is to deliver them. Evaluation studies in community care settings often fail to provide full details about the intervention, making it difficult to judge what was actually delivered. The characteristics of the research participants (carers and care recipients) are generally poorly described and very few studies appear to consider the fit between carers’ stated or assessed needs and the service provided (the notable exception being those interventions that included a comprehensive assessment).

Workshop participants cautioned that simple arguments about lack of evidence could be counter-productive, leading to abandonment of promising and innovative types of services. Weaknesses in the literature are not unique to carer interventions, such as respite, but are common in community care. Indeed, the challenges in applying principles of evidence-based medicine to the field of public health have been widely acknowledged (Kemmm 2006; Ogilvie et al. 2005).

In addition, a great variety of outcome measures are used, some of which are not well defined (e.g., carer satisfaction). Workshop participants agreed that there needs to be more emphasis on the impacts of interventions on quality of life and/or subjective wellbeing. For this reason, it is preferable when summarising the results of studies to refer to the name of the scales used rather than to general concepts such as ‘stress’ or ‘coping’.

In many studies it is unclear what the purpose of the intervention is expected to be, whether it might benefit the care recipient or the carer or both. Further, many studies lack clarity about whether the goal of the intervention is therapeutic in the sense of addressing an immediate issue or preventive in the sense that the goals are longer term (like the sustainability of the relationship or delaying residential placement).

Caution is required in interpreting the findings of meta-analyses, as these can differ markedly according to how interventions are classified. It may not be obvious how to define a particular service. For example, regular meetings at which carers share their experiences with each others and listen to guest speakers on various topics (e.g., use of equipment, stress management, available services, alternative therapies) could be defined as ‘support groups’, ‘psychosocial support’ or ‘education’. The decision about how to classify an intervention study has profound implications for meta-analysis conclusions about effective types of interventions, particularly where there are relatively few studies in the review.

The fact that relatively strong evidence exists for multi-component interventions suggests somewhere in the mix is the ‘active ingredient’ that needs to be identified. Alternatively, this ‘active ingredient’ may differ between carers, because studies seldom start by assessing needs or describing carers in detail. It was agreed that both research and service provision would benefit from the collection of comprehensive assessment information from carers and care recipients, rather than the current situation of limited data collection tailored to the services on offer.

## **10.2 Additional evidence**

Workshop participants supplied additional material to assist with understanding carer needs, explaining the results and to highlight bodies of work that were under-represented in the draft report. There were 22 extra studies and reports submitted or searched at this point and the content of these were added into the relevant sections of this report. References to new and additional papers, books and reports were added, and brief additional paragraphs included in the executive summary and conclusions. None of the additional information changed the conclusions substantially.

The additional material on carers' needs was provided by Carers Australia and included a recently released report by Deakin University (Cummins et al. 2007) on carer health and well-being that was publicised in Carers' Week, 2007, a report on the Carers Mental Health Project (Nankervis and Mirapuri 2006), a market research report on the needs of single parents caring for children with disabilities (Stollznow Research & Insights Advisory 2005) and a newly released report by the Taskforce on Care Costs (2007).

A number of the groups attending the workshop (Carers Australia, Alzheimer's Australia, Aged and Community Services Australia and others) are members of the Community Care Coalition that commissioned a report on 'The Future of Community Care' by The Allen Consulting Group (2007). That report included strategies for developing more active, flexible and consumer directed models of care, with more attention to measuring outcomes for clients, and in particular the importance of improving the flexibility of, and access to respite care (pp.40-42).

A third report was produced for the NRCP by the Australian Longitudinal Study of Women's Health on employment transitions and exploring a measure of resilience, and that report was received by the Department in October 2007 and included in the section that describes that series of reports (Watson et al. 2007).

Studies by Ken Pakenham and colleagues (2001, 2002, 2005, 2006 and 2007) focussing on multiple sclerosis and positive models of coping were included in the final update of the literature, as was the concept of resilience (Deveson 2003), which had not been included in the initial search terms as the primary focus was on carer burden. Additional work on caregivers of people with dementia by Henry Brodaty and his colleagues that had only been covered in the search strategy at the level of systematic reviews was also included (1992, 1994, 1997 and 2005).

An Australian study by Zapart et al. (2007) covered the carer's perspective on home-based palliative care in Sydney. Carers were interviewed to assess the care recipient's care needs and the informal care that was provided and used the SF36 form to measure the health status of the carer and open-ended questions to get at what support would be most helpful. Domestic assistance, personal care, medications management and organisational tasks were where help was most needed. Carers' mental health scores were lower than the Australian norms. The extra support required was for information, in-home respite, help with household tasks and financial support.

Examples of the use of Goal Attainment Scaling in personalising the measurement of outcomes were emphasised by participants at the Workshop as an important adjunct to the use of other standard measurement scales and these have been followed up and included in this review (Rockwood et al. 2006 and 2007).

The Australian Institute for Family Studies drew attention to important work associated with one of their researchers who used a sample from Melbourne in a randomised controlled trial of family grief study interventions in palliative care and bereavement (Kissane et al. 2002, 2003 and 2006). This body of work had been missed by the search strategy in the attempt to limit the inclusion of the large volume of psychology-focused material available on the effectiveness of family therapy interventions.

### **10.3 Standardised assessment and outcome measures**

It is clear from the review of the literature and current practice in Australia that there are opportunities to harmonise the use of key questions relevant to carers and their support needs in national surveys and routine data collections. This work would support the progressive development of a common language of carer support and more standardised approaches to information sharing, in order to reduce the problems created by agencies and organisations continually reinventing similar but non-comparable ways of collecting information. The key product would be a series of 'lessons for service delivery', or foundations for practice, using a base of evidence about effective interventions and a method of thinking about for planning.

The related issues of *Goal Attainment Scaling* methods being more explicitly incorporated as part of the standard assessment of carers and consistent or 'harmonised' measurements of outcomes were described as central to a future agenda for both practice and research in supporting carers. These topics were discussed extensively at the workshop and are elaborated below (Sections 12.1, 13.1 and 13.5).

#### **10.4 Workshop evaluations**

An evaluation form was circulated to all participants following the workshop, seeking their views on the workshop and any additional references they felt should be included in the final report. Eight responses were received from a range of provider, consumer and researcher groups, with the majority being overwhelmingly positive about the day.

Five respondents indicated that the day was useful, whilst 3 said it was partially useful. Comments included 'the literature search was very thorough', 'extremely useful as it gave a summary of the current status of research and evidence for various types of interventions with carers', 'a good opportunity to gain feedback from all areas, researchers, department, providers and carers', and, 'it gave me an idea of all the research that is available ... and where to be able to access it when we are planning for services'.

There were some respondents who felt the report missed some key issues. One service provider was concerned about the absence of action research and current practice, 'result(ing) in an almost redundant and outdated view of carer services', whilst another considered there should have been 'more carers attending and participating given the workshop was about issues involving them'. The absence of research on ATSI and CALD groups was a particular concern raised by a number of respondents.

The feedback to the question regarding opportunities to convey views and perspectives was more mixed. While most acknowledged the opportunities given to participate and respond to the findings in the report, the overwhelming sense was that more time was needed, especially given the volume of material in the report and range of issues covered. One participant suggested that it 'would have been more useful to concentrate on generation of ideas and strategic planning based on the Report'.

The lack of time to analyse the content, given the volume of what was presented, was identified as a major weakness of the day. One respondent suggesting 'perhaps there needed to be a 2 day process (separated) with day 1 outlining and discussing the outcomes of the literature review and day 2 providing the opportunity for considered input'.

Respondents overwhelmingly acknowledged that a key strength of the workshop was the range of stakeholders and the quality of the facilitation of the day. As one person summarised, '(g)ood collection of people, good focus, worthwhile discussion group'. Anecdotal feedback from participants on the day and in subsequent communications, apart from the evaluation forms, confirmed that the workshop was appreciated by participants for its thoroughness of content and spirit of cooperative endeavour.

## **PART FOUR      IMPLICATIONS FOR THE FUNDING AND DELIVERY OF AUSTRALIAN CARER SUPPORT SERVICES**

The first task for the workshop was to identify priorities for improving routine services provided to carers. The following sections summarise the workshop discussions on this topic and integrate these with the findings of the review.

### **11      The match between the evidence and current practice**

Current practice in specialist carer support services (both government and non-government sponsored) in Australia has elements of high quality and innovative practices against a backdrop of mainstream services that effectively treat the role of carers as peripheral to the main task of providing formal services to the primary care recipient. Better understanding of the social and demographic context of an ageing population and finding ways of making the end of life worth living, are already making an impact on current practice and will continue to do so.

State and Territory legislation and policies have moved a considerable distance in the period from 2003 onwards in providing recognition of carers. The Carer Recognition Acts, Carers' Charters, and Action Plans with their principles and objectives attest to this. So too does the work on common approaches to assessment and care planning undertaken under the national community care reform agenda. There is more than enough alignment in policy and in common objectives and procedures across all jurisdictions to justify further work on building a truly 'national' approach to carer support that represents step-wise progress towards a more coherent 'system'.

Currently there are barriers to greater coherence in the approach to carer support because of the issue, shared by all the components of human service systems, of standardising approaches to collecting and effectively sharing common information. The language of carer needs and assessment and routine data collection has been standardised to some extent, and common approaches for surveys and localised needs assessment are more evident in current practice. While improving standardisation in any field is a huge and long term undertaking, there is now potential for moving the carer support sector much faster in this direction.

The quality of information about carers, their needs and the types of support they receive is potentially very rich and useful, but is not always consistent between the various programs areas and is unevenly used in planning the broader service systems.

The combination of national population surveys by the ABS and subsequent data analyses by the AIHW, plus the availability of studies using longitudinal data (such as the longitudinal study on women's health), time use data (such as the household income and labour dynamics survey) and more localised and specialised surveys (for example of carers of younger people with a disability), add up to an increasingly useful and consistent picture of carer needs. Issues for employed carers and those making the transitions to and from caring roles, and the mix of payments and incentives and practical support services they need, are just beginning to come more into focus for policy-makers. A common understanding of carers' needs should be capable of being organised into a coherent framework that could be translated into practical and common planning, assessment and resource allocation procedures. The workshop participants drew attention to research work where more coherent models of care, and stronger program logic models have evolved, for example in multiple sclerosis (Pakenham 2001) and in palliative care (Kissane et al. 2002)

The biggest challenge in improving the match between the evidence and current practice is in finding a common language in particular about how we understand and describe carer needs and in measuring the impact of what we do to meet those needs. The workshop represented a step forward in gaining a greater consensus on a "harmonisation" strategy, to borrow a useful term from the dementia outcomes research literature (Brodsky et al. 2002).

## 12 Future service development opportunities

This section highlights future service development opportunities under the areas of: understanding needs; access to services; service delivery models; gaps in the evidence; and translating research into practice. This section summarises the combined results of the literature review and the workshop.

### 12.1 Understanding carers' needs

More detailed information is required about carers, both as participants in studies and as users of services. The issue of assessment was felt to be fundamental to the future development of services for carers. There is as yet no combined and manageable minimum data set in community care, although there are plans for its development, and this would serve to decrease the burden on providers offering more integrated services across a range of programs. Workshop participants agreed that this 'gap' needed to be addressed.

There is a need for systematic collection of better assessment and re-assessment data on carers accessing carer support services and to use that information to both routinely measure carer outcomes and to benchmark carer support services. Existing clinical outcomes and benchmarking centres (e.g., the Australasian Rehabilitation Outcomes Centre, the Palliative Care Outcomes Collaboration and the Australian Mental Health Outcomes and Casemix Network) provide useful examples of such models.

Assessment should be broad and focused on the care situation and the goals for the carers and care recipients, rather than being mainly on eligibility for the services available. Deeper assessments may be required to understand the specific needs related, for example, to different care recipient diagnoses, pre-existing health and psychological conditions or multiple caring roles. Work on the CENA and ACCNA was acknowledged as an important step towards a comprehensive assessment process.

Carers often seek assistance in crisis situations. The assessment process should acknowledge that not all the necessary information might be collected in the first encounter and that the crisis may be related to the carer, the care recipient or both. In some cases the crisis may be created by bureaucracy as one form of respite or other support runs out of its allocated hours under program guidelines, but the need for assistance continues.

The assessment process should be meaningful to the carer and flow into appropriate and flexible responses from service providers. This would be facilitated by linking information from the carer assessment to that from the care recipient. Links to government data are also needed – it is currently difficult for small services to get access to such information (e.g. Australian Bureau of Statistics data are expensive).

Ideally, the assessment would acknowledge and validate the important role of the carer and be conducted promptly when required, leading to a timely service response. Service providers should consider the needs of the family unit in addition to the primary carer when designing a package of support. The assessor would act as an advocate for the carer in seeking services.

Workshop participants also raised the issue of potential conflicts between the needs of carers and those of care recipients. It is possible that some interventions may benefit one group to the detriment of the other. This raises questions about a carer's relationship with service providers and who is the client.

From the carer and service provider viewpoint, programs that support useful interventions (and researchers examining those interventions) focus too much on either the carer, or on the care recipient, rather than on both. Both have their own separate needs and carers have benefited from attracting attention to their needs in their own right. But the whole edifice will not work if services to support the care recipient are inadequate.

It was pointed out that loss and grief issues are relevant to many carers, not just those providing palliative care. For example, moving a family member into residential care can bring these issues to the surface, well before bereavement is an issue, and the need for this type of support at various points of transition may be greater than currently estimated.

It may also be the case that different care recipient 'trajectories' such as short or episodic or long term illnesses, which may lead to different carer experiences with the need for different types of resources to assist them in looking after those who are sick enough to die.

## **12.2 Access to services**

Workshop participants identified a need to answer questions such as:

- Who is receiving services?
- What are they receiving?
- How does service availability match to needs?
- What are the barriers to access?
- What additional services and/or resources are required in order to meet needs?

Such information would assist in planning services and also in selecting new interventions for trial and evaluation, and could be derived from studies of service distribution and utilisation, or routine data collection (see also Section 12.1).

There is a particular need for studies of service use among Aboriginal and Torres Strait Island people, people from culturally and linguistically diverse backgrounds and frail older people caring for their spouses. There is believed to be a great deal of unmet need in these groups, possibly because people do not necessarily identify themselves as carers and so do not seek services. Such people have been called 'hidden carers'.

Service providers must find a way to engage with these groups, both to promote existing services (by creating a 'carer identity' and demonstrating the benefits) and to develop new services that suit the range of carer needs and care situations.

Another group that presents a challenge for service providers is the ageing parents of adult children with disabilities. These people have often had a long career in caring. They may resist interventions that seek to establish the independence of their disabled adult child, because it means relinquishing some control and a loss of role, and sometimes they will have had poor earlier experiences with the service system.

These parents may also need assistance in planning for the future care of their adult child after their own death. This could include the various care options, estate planning and guardianship.

## **12.3 Service delivery models**

One of the major barriers to integrating services for carers is the number of separate funding models currently in place. Smaller services have less capacity to deal with these inefficiencies than do larger service providers.

Case management models appear promising and would not necessarily be an expensive way to overcome the complexity of the system. Different levels of case management support and various models of care coordination and 'navigation support' are operating in the carer support sector. Supported referrals, self-advocacy, understanding and effectively dealing with the maze of service types, care planning, and full case management are all important roles. Finding the best way of

matching the level of support offered to meet the goal of the carer, is a challenge for service development in the carer support sector.

These could link access to services with income support, and help coordinate carer services with those provided to care recipients. An alternative model would be to develop a suite of services for carers to purchase. The balance of advantages of providing cash versus services is not well understood in Australia and there was strong support among some workshop participants for trials of different delivery methods including vouchers and there are likely to be lessons from voucher systems for carers after they are implemented in the UK in 2008. While increasing choices for carers, these systems could disadvantage those clients without carers to benefit from them.

It was pointed out that many carers are currently living below the poverty line, as their caring role reduces their ability to participate in the paid workforce. Many carers with assets have sold property, used savings and dipped into superannuation funds to sustain the caring role after leaving employment. Programs to facilitate re-employment have the potential to assist these carers.

The workshop pointed to the need to emphasise more positive set of concepts that can supplement the notions of carer burden that so dominate the literature. It is not surprising that most academic attention has been paid to understanding burdens, but this has been to the detriment of understanding why is it that some people are managing and others are not. Work by Connor and Davidson (2003) describes the development of a new resilience scale, which may be helpful for building a more positive model.

In Australia, a book titled *Resilience* by Anne Deveson was published in 2003, and while having few references to the direct implications for service provision, it explores why some individuals and communities can overcome adversity and suffering while others are overwhelmed and despair. Models of care based on these more positive concepts have been described in relation to multiple sclerosis (Pakenham 2005) and the workshop participants emphasised they could have a much wider impact on service delivery models.

## **12.4 Gaps in the evidence**

A number of service sector priorities for building the evidence base were identified during the workshop discussions. There is great potential for increasing collaboration between service providers and researchers, both in evaluating current practices and in designing large trials of promising interventions.

Issues of particular interest to service providers include respite care, which needs to be better defined and better evaluated. More focus is needed on the effectiveness of specific types of respite (e.g. in residential aged care facilities). Some participants saw respite as a passive model of support, which could be compared with more 'empowering' models such as providing the appropriate level of case management and offering the most useful level of depth and duration of counselling.

Another area of interest is bereavement and other transitions such as relinquishing care. How and when support can best be provided to carers to ensure that they emerge from the caring role with no long-term health or emotional problems is an important issue for further research.

To date most research has been carried out in the public sector and little is understood about the impact of private services on carers. There is also a need to look at the impacts of changes to the broader service system, such as the introduction of Extended Primary Care (EPC) items for GPs and the FaCSIA/COAG funding for increasing mental health respite opportunities.

There was also interest in evaluating the role of assistive technology for care recipients and its effects on carer burden. This could include traditional equipment such as beds and lifts, communication devices (bracelets, call buttons) and newly developed 'smart house' technology.

## 12.5 Translating research into practice

Service providers were concerned about the prospects for applying interventions in the 'real world'. A number of strategies to enhance the likelihood of successful translation were discussed, including involvement of researchers in local service evaluations, providing training and establishing a clearinghouse of evidence-based practice in carer support.

Aggregating the lessons from pilot projects was seen as a promising approach for developing an evidence base around current practice. Researchers could work with service providers to help define what they want to achieve and identify outcome indicators and a range of valid, reliable and easy-to-use evaluation tools. In order for evaluation questions to 'line up' across studies, it would be necessary to agree first on a set of key outcome measures, which should be based on the goals of the carer (using individualised '*Goal Attainment Scales*').

The advantages of more individualised measures are that they can better reflect the diversity expected of a more flexible system of carer support. Such goals may include social connectedness and subjective wellbeing/quality of life for carers. The consistent use of standardised evaluation instruments related to the goals of interventions, in addition to individualised goals, would enable services to produce useful data on the effectiveness of interventions delivered in the usual service setting. It may then be possible to aggregate these results across projects to establish whether the intervention works in multiple settings.

Training is another essential component in the translation of evidence into best practice, both to communicate the findings of current research and to ensure that assessment tools are consistently used and their results interpreted in consistent ways. To avoid duplication of effort, links would need to be established between community care and primary care, hospital and community-based services, State-based programs, mental health services and other mainstream providers.

There was some support for establishing a single clearinghouse and dissemination function for the growing mountain of information on best practice in support services. The aim would be to meet the information needs of different groups of carers so that the duplication of effort in this direction can be minimised.

Carers Australia and its networks, including the condition-specific support organisations such as Alzheimer's Australia, already have an important information function for carers and care recipients. It should be possible (using web-based technology) to develop a distributed network that shares the common tasks of information giving and navigation support (i.e. to help carers move within and between the service sectors) and makes use of the best quality of information available in order to do so.

Examples of good practice highlighted at the workshop included a web-based catalogue, 'Surviving the Maze', which provides information on about 60 topics relevant to carers. This resource is provided by Carers Victoria and is tailored to be relevant for each state and territory. The opportunity of building on this already well developed national resource by making use of the findings from the literature in subsequent updates or new versions of this 'Fact Sheet' format was noted in the course of the workshop.

There are also examples in the international literature such as the material prepared by Carers UK, as well as other examples of Australian national and state-based work supported by Carers Australia that supports a role in the dissemination of information to carers and care recipients.

In addition to carers and care recipients, there is also a need to make the best available evidence available to service providers and researchers. Some attempts to achieve this have already begun but there is, at yet, no national approach. As one example, the Benevolent Society of NSW provided information on their continuing efforts in translating research evidence into practice in community-based aged care with the Social Policy Research Centre (SPRC). They convened a workshop earlier in 2007 to canvass ideas about ways of improving the exchange of knowledge

between researchers and practitioners in the field and have decided to develop a series of 'Research to Practice Briefings' in partnership with the SPRC.

An international example of a broader national approach is the Canadian Health Services Research Foundation's approach to 'knowledge transfer and exchange' (see [http://www.chsrf.ca/home\\_e.php](http://www.chsrf.ca/home_e.php)). This is a national strategy to bridge the gap between researchers and decision-makers.

A carer research clearing house, which would appropriately be provided by a national institute such as the Australian Institute of Family Studies or a university research centre, would have a more technical role. This would include:

- Analysing and synthesising research findings.
- 'Research translation' including the development of agreed national outcome measures and training in outcome measurement for both service providers and researchers.
- Dissemination of research findings in ways that are useful for service providers (e.g. translating research findings into practice guidelines).
- Providing advice to government on the strength of evidence for different types of carer support interventions and on priorities for future research.
- Promoting cooperation and information sharing between researchers, policy makers, practitioners and carer representatives.

This would require appropriate infrastructure, support from library resources to capture international developments and a network of experienced researchers in the field. The Australian Health Outcomes Collaboration (see <http://chsd.uow.edu.au/ahoc/>) is a good example of what can be achieved with a longer term strategy in this area of promoting promising and well-supported, as well as strongly evidenced-based, practices. Another example is CareSearch (see <http://www.caresearch.com.au/home>). CareSearch is an online resource of palliative care information and evidence. All materials in CareSearch are reviewed for quality and relevance. Different sections of CareSearch are targeted to:

- Patients, carers, families and friends
- Health care providers
- Researchers and palliative specialists.

## PART FIVE IMPLICATIONS FOR FUTURE RESEARCH

The second task for the workshop was to provide input towards a coherent research and development agenda. This section summarises the workshop discussions on future directions for research, mapping (where possible) to similar themes raised in discussions about future directions for service provision. Finally, the workshop discussions and literature review findings are brought together in a framework for a future research agenda.

### 13 Key questions for future research

This section outlines the key questions for future research in the following areas: understanding carers' needs; access to services; service delivery models; gaps in the evidence, including for respite care; outcome measures; research design and methods; and translation of research into practice.

#### 13.1 Understanding carers' needs

The research agenda must include the capacity to identify the current and future un-met and under-met needs of carers. On all of the available evidence, the number of Australian carers will increase, as will the competing demands on them. Identifying the needs of Australian carers, and producing and using the best available evidence to meet their needs, should be a national priority.

At the workshop it was agreed that further study is required to understand the specific needs of some carer groups, particularly:

- Frail aged and co-dependent spousal carers, including ageing gay couples
- Young people both as primary carers and as family members
- Aboriginal and Torres Strait Islander people as carers and care recipients where remote locations, access to formal supports and cultural factors influence the responses to their needs
- People from culturally and linguistically diverse backgrounds
- Carers for people with younger onset dementia
- Employed carers and those seeking work around their caring roles

Some members of these groups may not identify themselves as carers and this will be a challenge for future research.

It was agreed that new studies to evaluate current services and promising interventions should include a detailed description of the carers and care recipients who take part. This should include information about family and housing situation, multiple caring roles, health and psychological conditions that existed prior to the caring role, and other aspects of the care situation that may influence outcomes. This would be facilitated by the implementation and collection of a minimum data set in community care.

Longitudinal studies in Australia have revealed the extent of 'turnover' in the caring population year by year, suggesting that for many people the caring role is a temporary career through which they pass and eventually emerge. It is important to better understand the transitions in this career more closely and to look at typical outcomes and the influences on outcomes.

This line of research could be tied in with the concepts of resilience and survivorship. These can be seen both as an individual difference between carers and as a product of the caring situation at a given moment in the carer's career. An understanding of factors associated with resilience would be useful in designing interventions that build on carers' strengths.

It may be possible to target interventions more effectively, not just by identifying vulnerable people, but also vulnerable time points at which interventions are most needed. This research work would provide a balance to the negative aspects of caring that has dominated the literature to date.

### **13.2 Access to services**

It was suggested that patterns of service use by carers and care recipients are not well understood in Australia. The literature search generally supported this view and there was one study that examined carer survey data to look at why carers don't use services. This was a study of the non-use of services by carers of people with dementia and it showed the key factors were that they were managing at the moment, had a reluctance to use services, there were service characteristics that impeded their use and some carers just don't know of the existence of services (Brodaty et al. 2005).

Further studies could explore the demography of service delivery, the distribution of need versus availability of services, barriers to access, and the costs of providing services in different settings and to different family types. This could shed light on the reasons some groups are under-represented in accessing services for carers, particularly Aboriginal and Torres Strait Islander people, those from culturally and linguistically diverse backgrounds, and older carers looking after their spouses. One possibility is the use of data from the 2006 census, which included questions on caring and unpaid work that could be examined by location to look at the match between needs and provision of services.

Existing data sources such as the census and ongoing longitudinal studies could also be used to identify 'hidden' carers (those who do not identify themselves as carers). Population studies could also be conducted to address this question. Carers who postpone seeking services until a crisis situation develops may become physically exhausted and suffer emotional and health consequences in the long term. Studies exploring the attitudes and needs of these groups could be a first step towards developing more appropriate ways of delivering services to these carers and encouraging them to seek help.

A related question, and one that is key to the delivery of effective interventions once they have been identified, is whether there is sufficient capacity in the Australian workforce to provide the services required. Otherwise, interventions that have been evaluated in research settings and found to be working may not be made widely available to carers. There is a need for research into workforce issues such as:

- Who can deliver interventions to carers?
- How many workers are there in each field?
- What are their qualifications and what further training do they need?

Such research would provide a foundation for understanding what types of carer services might work in the Australian context.

### **13.3 Service delivery models**

There was strong interest from some carer representatives in exploring alternative funding and delivery arrangements. It was suggested that consumer-directed models that have proved successful elsewhere should be trialed in Australia. In particular, the following concepts were felt to be worth testing:

- Providing carers with vouchers rather than services
- Providing tailored services rather than standard packages

These kinds of trials are, in theory, possible within existing services. For example, a carer respite centre that currently has a brokerage model in place could be a setting for a trial of consumer-directed care.

There is evidence that delivery of interventions via one consistent service provider is more effective than delivery by several providers. For many carers and care recipients, the General Practitioner is the first port of call when support is needed. It would be useful to study the needs of service providers, including GPs and community care workers, in providing help to carers. What knowledge do they have, and what additional training and/or resources might be helpful?

One of the better-supported intervention types is case management. Further research is needed to establish the effectiveness of this approach in the Australian context. Any future studies should be informed by current work, for example in mental health, where the value of case management is being challenged. Would each carer benefit from a case manager, or would it be preferable to reduce the complexity of the system so that consumers can navigate it independently?

### **13.4 Gaps in the evidence**

The discussion and the additional research material supplied by the Workshop participants highlighted and reinforced some of the gaps identified in the review of the literature.

Additional studies of carers' needs add little that is new to the overall picture but it is in the specific details that much is yet to be described in ways that can help the field. This includes investigating the sub-groups of carers that have been not yet investigated in any detail or at least reported in the literature. Remote and rural and Aboriginal carers are an obvious group where more work is required, especially in relation to different types of family arrangements.

The Workshop discussion showed that useful work is going on at present on young carers, grandparent carers and single parent carers and again the point was that this work is yet to influence the service sector in widespread or practical ways (Pakenham et al. 2006 and 2007, Cass 2007).

The needs of co-dependent carer couples are complex and the role of services and service complexity in meeting their needs (or not) is still in need of further identification, as is the changing mix of formal and informal care that constitutes the service 'maze' in Australia.

The third report on women in mid-life by the Australian Longitudinal Study of Women's Health and the HILDA survey reports show the benefit of continuing work on employment transitions and investigating the 'turn-over' that is evident as people move in and out of the cohort of carers over the course of their lives.

There are some very useful models of coping and distress and these provide useful theoretical bases to explore the caregiving arrangements of Australians in more detail. More examples in the Australian context of the use of *Goal Attainment Scaling* in personalising the measurement of outcomes were emphasised as a useful direction for further research, as was the concept of more individualised funding models that promote consumer choice rather than a dependency on what formal services have to offer.

#### **13.4.1 Respite**

One of the foremost questions for workshop participants was "Why is there so little evidence on the benefits of respite care?" Methodological problems with the studies evaluating respite have been well documented in previous reviews (Flint 2005; Lee and Cameron 2004; McNally et al. 1999), although a more recent review concluded that respite provides a small reduction in burden and a small improvement in physical and mental health to carers of frail aged persons. That same recent review also commented on gaps in the evidence (Mason et al. 2007a, p. 298):

*“However, much of the existing literature is unable to inform current policy and practice: there are many important gaps in the knowledge base, with a lack of recent, good quality, controlled evaluations for all types of respite care and no economic evidence for any type of respite other than day care. Given the changing demographics of the industrialized world, the ever-pressing need to ensure that limited resources are spent wisely and effectively, and the moral imperative to properly support frail older people and their caregivers, high-quality, robust research is urgently needed.”*

Discussions at the workshop focused initially on the definition of outcomes and the importance of understanding what carers want from respite. There is a need to unpack and define the meaning of respite and its expected effects in the context of a systematic model of caring. These effects may well differ among carers depending on factors such as the characteristics and diagnosis of the care recipient and the care situation. It would be feasible to conduct a systematic evaluation of respite, varying factors such as type, dose and timing. It is also important to understand the factors that lead to a need for respite, and whether these can be predicted. Conversely, why do some people resist respite care? It was agreed that there was considerable demand for respite: most carers say they need it. Given this fact, the question for research is “what kind of respite works best (in what circumstances)?”

### **13.4.2 Other topics**

Few other specific interventions were mentioned by workshop participants as priorities for further research. There was, however, strong advocacy for providing research support to enable service providers to evaluate current, innovative practices. This issue is explored in more depth below (Section 13.6).

One area that was mentioned was the possibility of identifying interventions that have proved successful with some groups (e.g. parents of children with disabilities) and applying them more widely to other carers.

The workshop highlighted the value of exploring ‘resilience’ as an attribute and as an explanation for why some carers require fewer services than others and why some carers can endure crises better than others. Similar theoretical approaches were highlighted in Pakenham (2005) on the positive impact of multiple sclerosis (MS), carer benefit finding and positive and negative adjustment.

The financial costs of the caring role are well documented. This raises questions about how best to ensure that carers are not living in poverty, either by improving access to employment or providing income support.

While the focus of the current review was on primary carers, some studies have shown that interventions involving both the carer and the care recipient are more effective than those delivered to one or the other. Future research could also move beyond the primary carer and the dyad to consider the family as the unit of care, measuring different types of impacts on family members and exploring ways to resolve areas of conflict between the needs of carers and those of care recipients.

### **13.5 Outcome measures**

There was much discussion about the need to define outcomes appropriately and measure them consistently. It was suggested that carers, service providers and government departments may have different perspectives on outcomes. For example, service providers may see the goal of care as “sustaining the caring relationship and delaying entry to residential care”, whereas carers may see it in more practical terms, for example, “Can I get to the shops?”

For this reason, it was agreed that any attempt to define outcome measures should begin with a consultation process in which carers are asked about the outcomes most meaningful to them. These may include:

- Knowledge
- Capacity for control and choice
- Maintaining other roles and 'continuation of life'
- Building on strengths/resilience
- Alleviating difficulties
- Preventing long-term adverse effects (health, financial, etc)

Some workshop participants advocated the use of *Goal Attainment Scaling* or similar methods to provide individualised measurement of outcomes that can be more responsive than standard measures because it is personalised. These methods have been applied successfully for many years in fields such as psychotherapy, although their usefulness in the context of carer support has been only minimally investigated in the academic literature (Rockwood et al. 2006). It was also suggested that these personalised measures (when linked to needs assessment) could be combined with more general, holistic measures. In particular, delegates felt there should be more emphasis on the measurement of quality of life or subjective wellbeing outcomes for carers.

Caution and rigour are needed to ensure that outcome measurement is specific, avoiding more vague concepts such as 'satisfaction'. Valid and reliable instruments should be used and adequately described in research reports. Defining appropriate outcome measures also requires close attention to the nature of the intervention and its expected effects. Evaluation studies should begin with a well-developed model of caring with an explicit statement about the goals of the interventions, such as whether they are therapeutic or preventive, as well as an expected timeframe of beneficial effects.

The discussion of outcome measurement highlighted the need for ongoing or standardised data collection to allow continuous evaluation, quality management, and comparison between services. There is considerable potential for harmonising the collection of outcomes data, and for the creation of a carer outcomes measurement suite. The evidence from the current review indicates that a suite of more formally endorsed and accredited resources including information 'packages', measures of activities, impact and outcome, and routinely used data collection tools might be promoted in the sector. This would build on work already well underway on improving assessment for services, the accessibility of websites, expanding the range and modalities of delivery of tailored information for specific groups of carers, and providing common tools for monitoring the regional impact of the various carer action plans.

The rationale for this harmonisation strategy can be promoted for a number of purposes:

- To encourage common (and more evidence based) ways of providing information, measuring the needs and enhancing the capacities of carers
- To generally enhance the planning and resource allocation capacity in the care support sector
- To specifically encourage more reliable local comparisons to be made with national and state/territory statistics in order to create local carer support profiles and reliably document gaps and unmet need in the formal and informal service sectors.

In essence, harmonisation creates a common language for communication across the sector.

### **13.6 Research design and methods**

The carer research literature contains multiple recommendations for well-designed randomised controlled trials and, in our view there is no doubt that these are required to strengthen the evidence base for carer interventions. That said, the methodological challenges in conducting better (and more powerful) studies should not be under-estimated.

The objective of a recent systematic review was to determine the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their caregivers. To identify relevant studies, 37 databases were searched, and reference checking and citation searches were undertaken. Well-controlled effectiveness studies were eligible for inclusion, with uncontrolled studies admissible only in the absence of higher-quality evidence. Studies assessed the effect of community-based respite on caregivers of frail elderly people relative to usual care or to another support intervention. Eligible economic evaluations also addressed costs, and where appropriate, data were synthesized using standard meta-analytic techniques. Ten randomized, controlled trials, seven quasi-experimental studies and five uncontrolled studies were included in the review. The conclusion by Mason et al. (2007a, p. 290) was:

*“Given the increasing numbers of frail elderly people and the lack of up-to-date, good-quality evidence for all types of respite care, better-quality evidence is urgently needed to inform current policy and practice.”*

Despite the challenges of competing for resources with research where controlled trials are easier to design, there is a strong case to promote and support such studies through the peer-reviewed grant processes of the National Health and Medical Research Council, Australian Research Council and other research funding bodies. In the process, the research implications of relevant studies to date (see Attachments 2–5) need to be considered. However, caution should be exercised to ensure that the research agenda remains relevant to the needs of the support sector and is not diverted into more narrow medical or academic pursuits. There is a lot to be said for alternative funding to the NHMRC sources in promoting innovation that is more relevant to the concerns in the field.

From the perspective of those funding carer support services (primarily the Department of Health and Ageing and the Department of Families, Community Services and Indigenous Affairs and to a lesser degree, the states and territories), the priority is undoubtedly to better evaluate the effectiveness of those interventions currently being funded and to use the best available evidence to inform future funding decisions.

In this regard, it is important to distinguish between efficacy and effectiveness:

- **Efficacy** - the level of benefit expected when health and community care services are applied under ideal conditions
- **Effectiveness** - the level of benefit when a health or community service is rendered under ordinary circumstances by average practitioners for typical clients/patients.

Funding bodies need to be concerned primarily with effectiveness. Evaluations of current practice, if well designed, have the potential to fill the key gaps that currently exist in the literature, specifically in evaluating different models of care and payment arrangements (including dose effects) and the effectiveness of different interventions for different types of carers.

The relative value of different research methodologies and approaches was debated during the workshop plenary and breakout sessions. Rather than seeing this as a choice between qualitative and quantitative, or between evaluations of current practice and large controlled trials, it is perhaps more productive to consider which combination of approaches are most useful for addressing a particular kind of research question.

Much innovative work is currently under way among Australian service providers, but it is largely invisible and inaccessible to researchers as it does not appear in the published literature. If an evaluation is carried out, it may not even be reported in detail within the sponsoring organisation or appear on its website. There is potential to close the gap between research and practice by facilitating close working between the two communities, so that service providers are given

assistance to evaluate their own programs. Action research and qualitative techniques are appropriate for these purposes.

Service evaluations can be useful as a way of understanding the dynamics of an intervention, exploring implementation issues and identifying possible mechanisms or 'active ingredients'. This information can be fed into larger, more systematic trials. There is a need to put researchers in touch with what is happening in the field, and to build evaluation into large programs and service innovations. The development of a national carer research clearing house as proposed in Section 12.5 would help with this process.

It was agreed that large trials of promising interventions are needed to establish effectiveness. These should employ rigorous comparison methods (e.g., randomised controlled trials, waiting list control designs, econometric techniques in which known confounding factors can be controlled statistically). Delivery of the interventions should be standardised and there should be careful selection of outcome measures. It would be necessary to recruit large samples of carers for such studies and provide detailed descriptions, preferably including a standard assessment of needs. One participant pointed out that the existing waiting lists for services could provide 'natural comparison groups'.

Workshop participants identified a number of potential funding sources for research on effective caring that could be used to take the momentum of the literature review forward with the assistance of those groups already well immersed in the carer support field. These sources include those that would be responsive to collaborations between universities and innovative carer service and support organisations, using applications for NHMRC (Ageing Well, Ageing Productively) and ARC linkage grants, with an emphasis on practical outcomes for the field.

### **13.7 Translation of research into practice**

Another benefit of linking the practitioner and research communities more closely is the opportunity to facilitate translation of research into practice. One strategy recommended by workshop participants was to involve service providers in the design of large trials, so they can provide input on whether the proposed intervention is feasible and could be implemented. Another strategy is the provision of sufficient resources for a well managed rollout of evidence-informed practice in the field. The Department could play a central role in this process of bringing practitioners and researchers together. Alternatively, this role could be undertaken by a carer research clearing house (see Section 12.5).

### **13.8 A proposed research agenda**

Workshop participants raised a diverse range of issues, some of which may at first glance appear contradictory. The challenge in formulating a research agenda is to bring these perspectives together coherently and fairly, ensuring all the voices are heard. A useful framework for this is provided by Campbell and colleagues (2000) who described a continuum of increasing evidence in complex interventions designed to improve health.

This framework (see Table 7, page 93) reconciles the apparent conflicts between the need to describe and evaluate current, innovative practice and the need for high quality evidence on what interventions are most effective and provide best value for limited resources. It positions the various activities and methodologies as steps on a path of research and development. Each makes a valid contribution to defining and developing a complex health intervention (e.g. respite care), identifying its active components and suitable outcome measures, and understanding its effectiveness. Movement between the different phases of research and development is an iterative process, as previous phases are reconsidered in the light of new information.

The process begins with a 'preclinical' phase, during which evidence is gathered on potentially useful interventions. This has been the task of the current review. In addition, the theoretical

basis for interventions is reviewed as a first step towards specifying the 'active ingredients' and the expected impacts.

- Qualitative methods and descriptive studies are used to develop a clearer understanding of the components of the intervention, how they might interact and the expected impacts on the target population (Phase 1).
- Small-scale pilot studies and service evaluations help to define the most appropriate delivery methods, the essential components of the intervention (and those that can be adapted or omitted), suitable comparison groups and useful outcome measures (Phase 2).
- After this process of development, during which the intervention and its expected impacts are clearly defined, it is time for large-scale experimental or quasi-experimental trials to establish credible evidence of effectiveness (Phase 3).
- Finally, attention turns to implementation and whether the intervention can be supported, sustained and replicated in other settings (Phase 4).

This framework can be applied to the question of identifying, testing and implementing effective interventions for Australian carers (Table 7). Workshop participants agreed that there is a need for greater precision and standardisation in defining outcome measures for intervention studies. At the same time, these need to be meaningful to individual carers.

The comment from one participant, who asked "How can carer satisfaction be high [following an intervention] but burden still be high?" is revealing. This indicates a basic problem with conceptualising outcomes, namely the lack of reference to models of how interventions might influence the lives of carers and care recipients, as well as their family situation and living circumstances. While a researcher may argue that satisfaction and burden are two separate constructs, not opposite ends of a spectrum, this may be less than obvious to practitioners designing an evaluation of an innovative local service for carers. This example highlights the importance of having a systematic model of caring underpinning interventions, not just the simplistic application of pre- and post-testing.

What is needed is a shared model of how and why interventions might work and a shared language to describe carers, interventions and their effects. This will facilitate communication between service providers and researchers, so that the findings of qualitative studies and local service evaluations can inform larger-scale experimental studies to produce high-quality evidence of effectiveness. By involving practitioners and service providers in the design of such large-scale studies, researchers can enhance the likelihood that the results will be relevant to the Australian context and there is the capacity and motivation to implement them.

**Table 7 Framework for proposed research agenda in effective caring**

Phase	Goal	Activities	Key questions
Preclinical	Review the evidence and consider relevant theory	Literature reviews Review models of caring Develop assessment tools	What do carers need? What interventions are promising? How might they work?
Phase 1	Model the intervention and define outcomes	Qualitative studies (focus groups, case studies, preliminary surveys) Descriptive studies of new or existing services and practices Carer needs studies, including longitudinal data on transitions and population studies to identify 'hidden' carers Studies of service use, demand and availability Studies of workforce capacity	How might this intervention work? Who needs it? What outcomes are important? What are the potential barriers to implementation?
Phase 2	Exploratory trials to investigate potential effectiveness and feasibility	Service evaluations Pilot studies Small scale studies with comparison groups or pre-post designs Development or adaptation of outcomes instruments Qualitative data to shed light on processes and provide a basis for interpreting quantitative findings	How should the intervention be delivered? What are the essential components? What components can be adapted/varied in different settings? With what suitable alternative can we feasibly compare the intervention? What outcome measures are useful?
Phase 3	Large trials	Rigorous tests of fully defined interventions, with large samples, credible comparison methods and adequate statistical power, incorporating needs assessment of participants and standardised delivery of services	Is the intervention effective in the setting where it is most likely to be implemented? Who benefits most/least? What factors in the delivery processes are keys to success?
Phase 4	Implementation and observation	Provide information and resources to rollout evidence-informed practice to services Collect routine outcomes data for quality management and benchmarking	Does the intervention deliver improved outcomes for carers? Can improvements be sustained? Can the results be replicated elsewhere?

Adapted from Campbell, Fitzpatrick, Haines, Kinmonth, Sandercock, Spiegelhalter and Tyrer (2000).

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## Appendix One

### Carer resources found on websites

An examination of the internet was undertaken to supplement the core search for effective interventions or treatments in carer support. This search examined promising or emerging practices from the academic literature as well as reports that have not been published in the formal, peer-reviewed literature.

A first search involved examining the carer-specific and departmental web-sites, and a second search, which expanded on the first search, examined other web-sites identified in the international literature.

The table of sites below is followed by a short description of the content of each site.

**Table 8 Web-sites examined for the Effective Caring project**

<i>Type of site</i>	<i>Links</i>
Australian Departments	<a href="http://www.health.gov.au/">http://www.health.gov.au/</a> <a href="http://www.facsia.gov.au/carers">www.facsia.gov.au/carers</a> <a href="http://www.dva.gov.au/">http://www.dva.gov.au/</a>
Ageing Research Online	<a href="http://www.aro.gov.au/">http://www.aro.gov.au/</a>
Carer Resources	<a href="http://www.carersaustralia.com.au/">http://www.carersaustralia.com.au/</a> <a href="http://www.carersvic.org.au/BCFC/BCFC.htm">http://www.carersvic.org.au/BCFC/BCFC.htm</a> <a href="http://www.workingcarers.org.au/">http://www.workingcarers.org.au/</a> <a href="http://www.bensoc.org.au/director/whatwedo/carers.cfm">http://www.bensoc.org.au/director/whatwedo/carers.cfm</a>
Australian Carer Research	<a href="http://www.dementia.unsw.edu.au/DCRCweb.nsf/page/DCRC3">http://www.dementia.unsw.edu.au/DCRCweb.nsf/page/DCRC3</a> <a href="http://www.sprc1.sprc.unsw.edu.au/researchtitles.asp?MCatID=6">http://www.sprc1.sprc.unsw.edu.au/researchtitles.asp?MCatID=6</a> <a href="http://www.deakin.edu.au/research/acqol/index_wellbeing/index.htm">http://www.deakin.edu.au/research/acqol/index_wellbeing/index.htm</a> <a href="http://chsd.uow.edu.au/">http://chsd.uow.edu.au/</a>
Canada	<a href="http://www.von.ca/index2.html">http://www.von.ca/index2.html</a> <a href="http://www.pwd-online.ca/pwdta.jsp?&amp;lang=en&amp;fontsize=0&amp;ta=79">http://www.pwd-online.ca/pwdta.jsp?&amp;lang=en&amp;fontsize=0&amp;ta=79</a> <a href="http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=services_hcrs_e">http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=services_hcrs_e</a> <a href="http://www.homecarestudy.com/overview/index.html">http://www.homecarestudy.com/overview/index.html</a> <a href="http://www.chsrf.ca/home_e.php">http://www.chsrf.ca/home_e.php</a> <a href="http://www.vac-acc.gc.ca/clients/sub.cfm?source=services/vip">http://www.vac-acc.gc.ca/clients/sub.cfm?source=services/vip</a>
New Zealand Departments	<a href="http://www.moh.govt.nz/">http://www.moh.govt.nz/</a> <a href="http://www.veteransaffairs.mil.nz/default.htm">http://www.veteransaffairs.mil.nz/default.htm</a>
New Zealand Guidelines Group	<a href="http://www.nzgg.org.nz/">http://www.nzgg.org.nz/</a> <a href="http://www.nzgg.org.nz/guidelines/0030/Assess_Processes_GL.pdf">http://www.nzgg.org.nz/guidelines/0030/Assess_Processes_GL.pdf</a>
Carers New Zealand	<a href="http://www.carers.net.nz">http://www.carers.net.nz</a>
United Kingdom	<a href="http://www.dh.gov.uk/en/Policyandguidance/SocialCare/Deliveringadultsocialcare/Carers/NewDealforCarers/index.htm">http://www.dh.gov.uk/en/Policyandguidance/SocialCare/Deliveringadultsocialcare/Carers/NewDealforCarers/index.htm</a> <a href="http://www.carersuk.org/Home">http://www.carersuk.org/Home</a> <a href="http://www.bbc.co.uk/radio4/youandyours/careintheuk/calculator.shtml">http://www.bbc.co.uk/radio4/youandyours/careintheuk/calculator.shtml</a> <a href="http://www.shu.ac.uk/research/ceir/specialisms/inclusion-care.html">http://www.shu.ac.uk/research/ceir/specialisms/inclusion-care.html</a>

<i>Type of site</i>	<i>Links</i>
USA	<a href="http://www.aoa.gov/prof/aoaprogram/caregiver/caregiver.asp">http://www.aoa.gov/prof/aoaprogram/caregiver/caregiver.asp</a> <a href="http://www.aafp.org/afp/20001215/2613.html">http://www.aafp.org/afp/20001215/2613.html</a>
<b>Additional sites not specific to carers</b>	
Care Services Efficiency Delivery Programme (CSED)	<a href="http://www.csed.csip.org.uk/">http://www.csed.csip.org.uk/</a>
Scottish Intercollegiate Guidelines Network (SIGN)	<a href="http://www.sign.ac.uk/">http://www.sign.ac.uk/</a>
American Association of Retired Persons (AARP)	<a href="http://www.aarp.org/research/">http://www.aarp.org/research/</a> <a href="http://www.aarp.org/research/international/perspectives/oct_06_handy_LTC.html">http://www.aarp.org/research/international/perspectives/oct_06_handy_LTC.html</a>
Agency for Healthcare Research and Quality (AHRQ) Guidelines Clearinghouse	<a href="http://www.ahrq.gov/">http://www.ahrq.gov/</a> <a href="http://www.guideline.gov/">http://www.guideline.gov/</a>
US General Accounting Office	<a href="http://www.gao.gov/new.items/d04913.pdf">http://www.gao.gov/new.items/d04913.pdf</a> <a href="http://www.gao.gov/new.items/d02652t.pdf">http://www.gao.gov/new.items/d02652t.pdf</a>
Campbell Collaboration	<a href="http://www.campbellcollaboration.org/">http://www.campbellcollaboration.org/</a>
Sweden service integration and functional abilities	<a href="http://www.aarp.org/research/international/gra/gra_special_05/care_at_home.html">http://www.aarp.org/research/international/gra/gra_special_05/care_at_home.html</a>
New Zealand needs assessment coordinators	<a href="http://www.carers.net.nz/modules.php?op=modload&amp;name=News&amp;file=article&amp;sid=256&amp;mode=&amp;catid=327&amp;thread&amp;order=0&amp;thold=0">http://www.carers.net.nz/modules.php?op=modload&amp;name=News&amp;file=article&amp;sid=256&amp;mode=&amp;catid=327&amp;thread&amp;order=0&amp;thold=0</a>

### Australian departmental web-sites

Examining specific departmental web-sites, the Department of Health and Ageing's (DoHA) site contains a carer section that has useful resources and links.

<http://www.health.gov.au/internet/wcms/publishing.nsf/Content/ageing-carers-index.htm-copy2>

### National Respite for Carers Program (NRCP) funds:

- Respite Services;
- Commonwealth Carer Respite Centres;
- Carer Associations; and
- National Carer Counselling Program

DoHA has also sponsored the collaborative efforts of Ageing Research Online, aiming to post links to research associated with directly commissioned research or research conducted by organisations which receive some DoHA funding such as Carers Australia.

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

(FaHCSIA) site contains departmental information on carer benefits and allowances as well as links to relevant social policy research including the Household, Income and Labour Dynamics in Australia (HILDA) Survey.

<http://www.facsia.gov.au/internet/facsinternet.nsf/disabilities/carers-nav.htm>

FaHCSIA also oversees the implementation of measures to increase the level of social support and community based care provided to people with a mental illness or intellectual disability and their families and carers.

**The Department of Veterans' Affairs** (DVA) site <http://www.dva.gov.au/> covers information on respite care provided through the Veterans' Home Care program and support for veterans by related programs; in particular the Department of Veterans' Affairs' Clinical Pathways (originally developed in 2000) and their links with the Guidelines for the Provision of Community Nursing Care (updated

in 2007). This provides an information environment for the conduct of clinical interventions using a 'casemix' type classification system.

[http://www.dva.gov.au/health/provider/community\\_nursing/pathways/pathindex.htm](http://www.dva.gov.au/health/provider/community_nursing/pathways/pathindex.htm)

**Ageing Research Online** provides a gateway to a range of very useful developing practice by describing ongoing studies as well as links to published studies. This provided a description of the work published by Lewin et al. (2006) reporting early insights from a study currently being run by the Silver Chain agency in WA into a program of early intervention for HACC eligible clients to maintain their functioning and promote health called 'Home Independence - A New Paradigm for Home Care.' <http://www.aro.gov.au/aro/researchEntryView.do?id=2706&type=subject>

## Carer Resources

**Carers Australia** <http://www.carersaustralia.com.au/> provides a gateway for carers at the national level and has links to sites for each state and territory association as well as sites for carers overseas. A web-based catalogue, 'Surviving the Maze', which provides information on about 60 topics relevant to carers is provided by Carers Victoria and is tailored to be relevant for each state and territory. <http://www.carersvic.org.au/BCFC/BCFC.htm>

The **Working Carers Support Gateway** is a website to help people who are working and caring. <http://www.workingcarers.org.au/>

Organisations operating carer respite services and other community care agencies have their own websites providing access to resources and directories. For example the **NSW Benevolent Society** has a carer page with useful links.

<http://www.bensoc.org.au/director/whatwedo/carers.cfm>

## Australian Carer Research

A number of university-based groups have resources and publications on carer issues. This list of groups below is not complete.

The **Dementia Collaborative Research Centre**, led by the Queensland University of Technology (QUT) conducts research concentrating on those issues that affect Consumers and Carers within the area of social research and multidisciplinary care in dementia within five themes:

- Diagnosis, assessment and management of pain for people with dementia
- Carer and community issues
- Residential/industry models
- Quality of life, lifestyles, prevention of functional decline and acute care issues
- Palliative care and end-of-life issues

<http://www.dementia.unsw.edu.au/DCRCweb.nsf/page/DCRC3>

Collaborative partners in this undertaking are Alzheimer's Australia, Curtin University of Technology, Griffith University, Hammond Care Group and Latrobe University through ACEBAC. QUT, through management of the Centre will coordinate, undertake, facilitate, and promote reviews and research.

Deakin University hosts the **Australian Centre on Quality of Life** and this centre has undertaken surveys of carers using the Australian Unity Wellbeing Index.

[http://www.deakin.edu.au/research/acqol/index\\_wellbeing/index.htm](http://www.deakin.edu.au/research/acqol/index_wellbeing/index.htm)

The **Social Policy Research Centre** at the University of NSW undertakes a wide range of research projects that have relevance to carers and some are funded by FaHCSIA to support policy around carer benefits and payments. Examples accessible through the website include:

- Active Ageing: Inter generation transfers, caring networks and policies maintaining participation of older Australians and their carers.
- Young Carers (Costs, Impact on Welfare)
- Carers and Service Non-use
- Young Carers: Social policy impacts of the caring responsibilities of children and young adults
- Negotiating Caring and Employment
- Time for Caring: Determinants of Informal Care and Time Use Data

<http://www.sprc1.sprc.unsw.edu.au/researchtitles.asp?MCatID=6>

The **Centre for Health Service Development** at the University of Wollongong developed the carer assessment tools for the NRCP and undertook the current project on effective caring. It has a long history of research on sub-acute and non-acute care, community care and measurement of health outcomes. <http://chsd.uow.edu.au/>

## Canada

### **Victorian Order of Nurses for Canada**

VON is a not-for-profit, national health care organization and registered charity offering a wide range of community health care solutions. <http://www.von.ca/index2.html>

VON was a founding partner of the Canadian Caregiver Coalition in 2000.

<http://www.von.ca/caregiving.html> VON produced a Caregiver Best Practice Manual for Community Health Providers in 2004 <http://www.von.ca/english/Caregiving/CaregiverManual/Manual.htm>

**Persons with Disabilities Online** is a Canadian government site that gives access to services and information for persons with disabilities, family members, caregivers.

<http://www.pwd-online.ca/pwdta.jsp?&lang=en&fontsize=0&ta=79>

Expanding the internet search to home support in general, indicated that Canada had the most detailed and relevant information on community based care available on the internet. Canada has developed, after a considerable period of consultation and development, a **Home Care Reporting System** (HCRS) using indicators of program effectiveness and quality, in order to enable comparison between the various provinces and territories. The system is designed to be capable of producing reports on the following issues (with the first official reports expected to be made in September 2008):

- access to home care services;
- health and functional status measures;
- clinical outcomes and waiting times; quality of care;
- informal support; and
- service utilisation by setting and provider type.

[http://secure.cihi.ca/cihiweb/dispPage.jsp?cw\\_page=services\\_hcrs\\_e](http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=services_hcrs_e)

Research groups in Canada have also undertaken detailed cost-effectiveness work (<http://www.homecarestudy.com/overview/index.html>). A recent expenditure study (**Canadian Institute for Health Information**, 2007) found that between 1994/95 and 2003/04 home health services (nursing care and health services) are taking up an increasing proportion of total home care services (home care services in the Canadian context include home health plus home support).

The **Canadian Health Services Research Foundation** supports the evidence-informed management of Canada's healthcare system by facilitating knowledge transfer and exchange - bridging the gap between research and healthcare management and policy. The CHSRF describes knowledge transfer and exchange as collaborative problem-solving between

researchers and decision makers. The web site describes the various avenues that have been developed:

- Research Use Weeks
- Promising Practices
- Knowledge Brokering
- Networks
- Exchanges
- Resources
- Knowledge Transfer and Exchange at Work
- Tools to help organizations create share and use research.

[http://www.chsrf.ca/home\\_e.php](http://www.chsrf.ca/home_e.php)

Another program described on the internet is the Veterans Independence Program (VIP) from Canada (see <http://www.vac-acc.gc.ca/clients/sub.cfm?source=services/vip>). It includes the following services: grounds maintenance (grass cutting and snow removal), housekeeping, personal care services, access to nutrition services, and health and support services; as well as out-patient health care, transportation costs, home adaptations, nursing home care. As can be seen this program is closely related to the Veterans' Home Care Program (VHC). VIP has had a full scale performance evaluation conducted recently with cost data, target data and an attempt to quantify cost savings by comparing the target veteran population with statistics for nursing home bed utilisation. This shows some evidence for the VIP program in "eliminating or delaying the need for institutionalisation". [http://www.vac-acc.gc.ca/general/sub.cfm?source=department/reports/deptaudrep/vip\\_baseline\\_dec\\_2006#02a](http://www.vac-acc.gc.ca/general/sub.cfm?source=department/reports/deptaudrep/vip_baseline_dec_2006#02a)

## New Zealand

The **New Zealand Ministry of Health** site provides a number of links to useful projects and reports:

- A research study of Young Carers that includes the development of a recording tool for agencies to identify young carers  
<http://www.moh.govt.nz/moh.nsf/indexmh/research-study-young-carers?Open>
- Evaluation of Complex Carers Group Project  
<http://www.moh.govt.nz/moh.nsf/pagesmh/5017?Open>
- Autism Services Interdepartmental Working Group  
<http://www.moh.govt.nz/moh.nsf/pagesmh/1456?Open>

Another relevant website was for **Veterans' Affairs**, linked to the New Zealand government, which covered case management to assist veterans to access particular services and the model is outlined briefly below. They use a brokerage model based out of a single centre in Wellington.  
<http://www.veteransaffairs.mil.nz/case-management/index.html>

**New Zealand Guidelines Group** <http://www.nzgg.org.nz/> has useful material relevant to carers under its site on assessment processes for older people.  
[http://www.nzgg.org.nz/guidelines/0030/Assess\\_Processes\\_GL.pdf](http://www.nzgg.org.nz/guidelines/0030/Assess_Processes_GL.pdf)

**Carers New Zealand** has a site that provides guidance to carers, access to research papers, news items etc and the site is being re-developed at the time it was accessed for this report.  
<http://www.carers.net.nz>

## United Kingdom

The UK web-site search found additional carer-related information and the volume of this information is considerable, so further detail is only provided on a limited number of sites and programs that stand out as being particularly useful.

The UK **NHS Policy on Carers** is available at the Department of Health site:

<http://www.dh.gov.uk/en/Policyandguidance/SocialCare/Deliveringadultsocialcare/Carers/NewDealforCarers/index.htm>

**Carers UK** was formed from the merger of two carer organisations with roots going back to the 1960's. Carers UK was set up by carers themselves and is still a member led organisation. Carers UK is the voice of carers. Their site is particularly useful, given the sheer size of the carer population in the UK (estimated to be six million), the level of sophistication of the Carers UK organisation, and the parallels in terms of the policy and service delivery context for Australian carers. The site gives access to resources that include research reports containing evidence of carers' experiences, statistics and policy recommendations, and a number of practical but more academic reports. <http://www.carersuk.org/Home>

The UK **Care Calculator** gives an approximate idea of the level of social care currently provided in parts of the UK. The site also contains a Care Questionnaire where the inquirer can contribute their views about the future funding of social care, and a Care Map, with links to Social Services and organisations across the UK which can offer expert advice and guidance on care in local areas. <http://www.bbc.co.uk/radio4/youandyours/careintheuk/calculator.shtml>

The **Centre for Education and Inclusion Research** (CEIR) is part of Sheffield Hallam University's research base within the Faculty of Development and Society, and is an amalgamation of former Centre for Education Research and the Centre for Social Inclusion. It has a research stream on care, carers and care workers that could serve as a model for 'packaging' evidence on best practice. <http://www.shu.ac.uk/research/ceir/specialisms/inclusion-care.html>

The site gives access to reports on the evaluation of policy interventions and research into paid care work, caring as an unpaid role and the situation of carers, especially those seeking to combine caring and employment. Research projects completed include:

- Local Challenges in Meeting Demand for Domiciliary Care (2004 - 2006)
- Part of the wider Gender and Employment in Local Labour Market research project this study focused on the supply and demand of domiciliary care, the characteristics of the sector's workers, and issues surrounding recruitment, retention and training in six local authorities.
- Social and Business Benefits of Employed Carers (2004 - 2006)
- This study, conducted on behalf of Carers UK, explored the social and business benefits of supporting working carers. The research examined the circumstances of carers who were in employment as well as identifying some of the challenges which organisations and individuals face in combining employment and caring. The study also explored innovative approaches in selected organisations where workplace cultures had altered to enable carers to continue in paid work.
- Evaluation of Action for Carers and Employment (ACE) (2005)
- A national evaluation of Carer's UK's EU EQUAL programme which also included the evaluation of the trans-national activity within the project, in association with F&M power (Austria). The project evaluated six ACE projects in England and Wales who were delivering support to carers who wished to remain in or re-enter employment.

## United States of America

The **National Family Caregiver Support Program** was developed by the Administration on Aging (AoA) of the U.S. Department of Health and Human Services (HHS). It was modelled in large part

after successful programs in States such as California, New Jersey, Wisconsin and Pennsylvania. The site provides an access point for information and assistance and includes a resource room and fact sheets. <http://www.aoa.gov/prof/aoaproq/caregiver/caregiver.asp>

The **American Medical Association** has a section of its site devoted to Caregiver Health in an effort to address the burden of caregiving through the development of web-based materials and information. <http://www.ama-assn.org/ama/pub/category/5099.html>

The site includes a caregiver self assessment tool to help carers to analyse their own behaviour and health risks and make decisions that will benefit both the caregiver and the patient. <http://www.ama-assn.org/ama/pub/category/5037.html>

The **American Family Physician** is a journal that has published a useful paper on-line by Parks and Novielli (2000) called 'A Practical Guide to Caring for Caregivers'. <http://www.aafp.org/afp/20001215/2613.html>

### Additional useful web-based information not specific to carers

Beyond the search of carers-specific sites the coverage was expanded to include home support in general. The search for relevant documents examined web-sites identified from the literature search. In terms of other, more general areas relevant to this work, a range of additional documents (mainly from the USA) on service delivery and innovative practice were found through the internet search.

The **Care Services Efficiency Delivery Programme** (CSED) provides links to innovative social care programs in the UK. It works collaboratively with all councils throughout England, supporting them to achieve 'sustainable efficiency' and improvements in adult social care. <http://www.csed.csip.org.uk/>

One of the CSED work streams is on 'Homecare Re-ablement' work that seeks to improve choice and quality of life for adults who need care, maximise long-term independence by appropriately minimising ongoing support required thereby minimising the whole life cost of care. There is useful link to a Retrospective Longitudinal Study (Version HRA 006: November 2007). <http://www.csed.csip.org.uk/silo/files/longit-study-bc.pdf>

Latest developments in policy advocacy for consumers are outlined in the **American Association of Retired Persons** (AARP) Re-imagining America (2006) document. In the area of home care, these include: the greater support of family carers (including financial and respite services); greater use of home and community care services rather than institutional care; greater use of consumer directed approaches; greater use of adult day care centres with transportation services provided; and the expanded use of volunteers. Additional areas of policy development are paying for performance in home care (rather than paying for services) and the increased use of technology or tele-health interventions [http://www.aarp.org/research/international/perspectives/oct\\_06\\_handy\\_LTC.html](http://www.aarp.org/research/international/perspectives/oct_06_handy_LTC.html).

Another policy development in the US is the need for the development of back-up services and systems when personal care services can not be provided on a particular day (e.g. personal hygiene, transfers from bed to a wheelchair, medications. See the **AARP** brief at: [http://assets.aarp.org/rgcenter/il/inb130\\_pcs.pdf](http://assets.aarp.org/rgcenter/il/inb130_pcs.pdf)

The **Agency for Healthcare Research and Quality** (AHRQ) database outlines a useful technological project to promote information sharing amongst providers covering the community care sector that can be found at: <http://www.ahrq.gov/qual/etransitions/etransitions2.htm#web>

Two recent reports from the US **General Accounting Office** are at <http://www.gao.gov/new.items/d04913.pdf> and <http://www.gao.gov/new.items/d02652t.pdf> and they highlight poor measurement of the home care workload and the unevenness in the availability of home care services in the VA system. This is in the context of a nation-wide reorientation of long term care services away from institutional care with home care moving from 15% of the US Medicaid

spending in 1992 to 37% in 2005 (see [http://assets.aarp.org/rgcenter/il/fs132\\_hcbs.pdf](http://assets.aarp.org/rgcenter/il/fs132_hcbs.pdf)) and a great deal of variability across states in home care service delivery on the ground (see <http://www.gao.gov/new.items/d021121.pdf>).

The **Campbell Collaboration** is an independent, international, non-profit organization that aims to provide decision-makers with evidence-based information for well-informed decisions about the effects of interventions in the social, behavioural and educational arenas. A Campbell Collaboration review of preventive home visits and their effect on functioning and mortality is currently underway.

[http://www.campbellcollaboration.org/doc-pdf/Protocol\\_Home\\_Visits\\_FINAL.pdf](http://www.campbellcollaboration.org/doc-pdf/Protocol_Home_Visits_FINAL.pdf)

**Sweden**, with its high expenditure on home care (0.82% of GDP) indicates there is still a need for better integration of services with health promotion and prevention; as well as a greater emphasis on maintaining functional abilities (see the comments on the Swedish experience by Dr. Britt Mari Hellner [http://www.aarp.org/research/international/gra/gra\\_special\\_05/care\\_at\\_home.html](http://www.aarp.org/research/international/gra/gra_special_05/care_at_home.html))

The **New Zealand Ministry of Health** (2002) completed an international review of coordination and integration of services. This work provides a useful historical perspective of policy and practice developments in the aged carer sector – including the issues of integration, assessment and respite care. Needs Assessment Service Coordinators National Contact List

<http://www.carers.net.nz/modules.php?op=modload&name=News&file=article&sid=256&mode=&catid=327&thread&order=0&thold=0>

### Implications of the web search

An issue for the future is that while there are many carer-related sites and a wealth of information, there are relatively few sites that can assist carers to navigate to relevant information.

There is an obvious gap to be filled by an independent body funded for looking at innovative and evidence based practice in carer support in the community and making that information more accessible.

The type of site that could fill the gap might be of similar quality to the US based Promising Practices Network in child and family health <http://www.promisingpractices.net/> or the California Evidence-Based Clearinghouse for Child Welfare <http://www.cachildwelfareclearinghouse.org>.

This indicates an important 'evidence gap' in the Australian community care context, that should be filled and would be a way to support the development of more effective practices.

## Appendix Two

### *Attendees at the National Effective Caring Workshop*

<b>Surname</b>	<b>First name</b>	<b>Job title</b>	<b>Organisation</b>
Ackland	Sean	Departmental Officer	Department of Health and Ageing
Best	Alex	Departmental Officer	Department of Health and Ageing
Bittman	Michael	Department of Sociology	University of New England
Brodady	Henry	School of Psychiatry	University of New South Wales
Bulsara	Caroline	Senior Researcher	University of Western Australia
Carroll	Barbara	Executive Officer	Tweed Valley Respite Service
Cross	Jo	Assistant Director	Department of Health and Ageing
Cummins	Robert	Personal Chair	School of Psychology
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Hegney	Desley	Director	University of Queensland
Higglet	Tracey		Applied Aged Care Solutions
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Hughes	Joan	CEO	Carers Australia
Jolly	Stephen	Business Manager	Care Options
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Pierce	Jill		Carers Australia
Ramsay	Lanna	State Director	Ozcare
Rankin	Helen	Director	Department of Health and Ageing
Rees	Glenn	National Executive Director	Alzheimer's Australia
Sajdovska	Verica	Respite and Aged Services Coordinator	Macedonian Welfare Association
Sadler	Paul	CEO	Presbyterian Aged Care NSW and ACT
Sheen	Colleen	Senior Policy Advisor	Carers Australia
Sinclair	Ron	Consumer	Alzheimers Australia
Sparrow	Pat	Policy Manager	Aged and Community Services Australia
Sparrow	Peter		Carer Support and Respite Centre Inc
Spicer	David		Campbell's Research and Consulting
Taylor	Gabrielle	Senior Manager	The Benevolent Society
Thompson	Cathy	Social Policy Research Centre	University of New South Wales
Tooth	Leigh	Senior Research Fellow	University of Queensland
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Vincent	Ben	Director	Department of Health and Ageing
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