Carers: Ageing and Disability

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CHAPTER 1  CARVERS IN AUSTRALIA
Who are carers?  1
About carers  2
What is a carer?  3
Key issues for carers  4
What might caring really mean for you?  5
Impact of caring  6
Carers in the bush  7
Women carers face a lifetime of health and economic consequences  9
Male carers need care too  11
Young carers in Australia  12
Older parent carers: exhausted, isolated and forgotten  13
National Carer Strategy launch  14
National Carer Strategy  15
Carers in Australia  16
The place of the National Carer Strategy  17
National Carer Strategy overview  19
The economic value of informal care  21
Caregiving doesn’t crowd out working  23

CHAPTER 2  INFORMAL DISABILTY AND AGED CARE
Disability, ageing and carers in Australia  24
Providers of disability assistance  26
The nature and impact of caring for family members with a disability in Australia  28
Disability care and support  31
Carers welcome disability insurance pledge  34
A national disability long-term care and support scheme  35
NDIS has the potential to vastly improve the lives of people with a disability and their carers  37
What the ‘Caring for Older Australians’ report means for the future of aged care  38
Caring for older Australians  39
New ways of thinking about care, and carers  40
Working with and supporting informal carers  41
Carers and end of life  46
Exploring issues – worksheets and activities  49
Fast facts  57
Glossary  58
Web links  59
Index  60
Carers: Ageing and Disability is Volume 342 in the ‘Issues in Society’ series of educational resource books. The aim of this series is to offer current, diverse information about important issues in our world, from an Australian perspective.

**KEY ISSUES IN THIS TOPIC**
Currently around 2.9 million Australians provide unpaid help and support to a family member or friend who has a disability, mental illness, chronic condition, terminal illness or who is aged and frail. Carers are a key but often unacknowledged part of Australia’s health system. The annual replacement value of care was estimated in 2010 to be over $40 billion.

Carers come from all walks of life, and spend on average about 40 hours per week providing care for many of the most vulnerable people in our community. At some stage in our lives, most of us will be, or need, a carer. Caring can be personally rewarding, but it is also a role with many demands and challenges, including financial hardship, strains on health and wellbeing, social isolation and career disadvantage.

This book looks at the invaluable role of the people providing informal aged and disability care in Australia, and explains the latest government initiatives aimed at supporting caregivers and those they care for. Isn’t it time we all cared about the carers?

The topic is presented in two chapters: Carers in Australia; and Informal disability and aged care.

**SOURCES OF INFORMATION**
Titles in the ‘Issues in Society’ series are individual resource books which provide an overview on a specific subject comprised of facts and opinions.

The information in this resource book is not from any single author, publication or organisation. The unique value of the ‘Issues in Society’ series lies in its diversity of content and perspectives.

The content comes from a wide variety of sources and includes:

- Newspaper reports and opinion pieces
- Website fact sheets
- Magazine and journal articles
- Statistics and surveys
- Government reports
- Literature from special interest groups

**CRITICAL EVALUATION**
As the information reproduced in this book is from a number of different sources, readers should always be aware of the origin of the text and whether or not the source is likely to be expressing a particular bias or agenda.

It is hoped that, as you read about the many aspects of the issues explored in this book, you will critically evaluate the information presented. In some cases, it is important that you decide whether you are being presented with facts or opinions. Does the writer give a biased or an unbiased report? If an opinion is being expressed, do you agree with the writer?

**EXPLORING ISSUES**
The ‘Exploring issues’ section at the back of this book features a range of ready-to-use worksheets relating to the articles and issues raised in this book. The activities and exercises in these worksheets are suitable for use by students at middle secondary school level and beyond.

**FURTHER RESEARCH**
This title offers a useful starting point for those who need convenient access to information about the issues involved. However, it is only a starting point. The ‘Web links’ section at the back of this book contains a list of useful websites which you can access for more reading on the topic.
WHO ARE CARERS?

THIS FACT SHEET FROM CARERS SA DEFINES AN OFTEN CONFUSING TERM

Carers provide unpaid support to a family member or friend who needs assistance. They may care for a frail aged person, someone with a disability, chronic or mental illness, or someone recovering from an illness or accident.

WHO CAN BE A CARER?

Carers come from all walks of life, all cultures and all religions. Some are only 10 years old while others are nearing 90. They may be spouses, parents, sons or daughters, siblings, friends, nieces or nephews or neighbours.

Over 2.9 million Australians provide help and support to a family member or friend – caring can happen to anyone, anytime.

Most carers give comfort, encouragement and reassurance to the person they care for, oversee their health and wellbeing, monitor their safety and help them stay as independent as possible.

HOW DO PEOPLE BECOME CARERS?

People become carers in different ways.

Sometimes it happens gradually – helping out more and more as a person’s health and independence get worse over time. It may also happen suddenly – after a health crisis (like a stroke or heart attack) or an accident.

It’s not uncommon for carers to feel that they don’t really have a choice. Even in large families the responsibility of providing care is often left to one person rather than being shared.

Many carers feel that it is what they should do.

WHAT DO CARERS DO?

Every care situation is different.

Some carers provide 24 hour nursing aid to a family member with high care needs. They help with daily needs and activities like feeding, bathing, dressing, toileting, lifting and moving and administering medications.

Others care for people who are fairly independent but may need someone to keep an eye on them or help them with tasks like banking, transport, shopping and housework.

Most carers give comfort, encouragement and reassurance to the person they care for, oversee their health and wellbeing, monitor their safety and help them stay as independent as possible.

Carers help their family members to have a good quality of life.

WHO DO WE SUPPORT?

The word ‘carer’ can be confusing. Many carers don’t use this word to describe themselves and it can sometimes be difficult to know whether we are the right organisation to help you.

We can help if you provide unpaid care and support to a family member or friend who is frail and elderly, has dementia, a mental illness, a disability, chronic illness or complex needs, or receives palliative care.
You do not need to live with the person you care for
You do not need to be the main source of care and support
You do not have to provide care every day or over many years
You do not have to receive the Carer Payment or Allowance from Centrelink.

Contact our advisory service if you have any questions about our services or about other supports available to you.

Over 2.9 million Australians provide help and support to a family member or friend.

OTHER TYPES OF CARERS

The term ‘carer’ is often used to describe roles and activities that are different to the ones supported by Carers SA.

We sometimes get contacted by people who mistakenly think that we provide services relating to these groups of people:

➤ Paid carers or care workers: are paid a salary or hourly rate to look after people with care needs
➤ Foster carers: are people or families who are paid to look after children and young people in their own home, usually because the young people are unable to live with their families
➤ Parents and carers: can describe anybody who lives with and looks after a child under 18
➤ Kinship carers: are relatives or close friends who look after children and young people who are unable to live with their families. For Aboriginal and Torres Strait Islander children, a kinship carer may be another indigenous person who is a member of their community.

ABOUT CARERS

FACTS FROM CARERS AUSTRALIA

Carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail aged. There are currently over 2.6 million unpaid family carers in Australia, more than 770,000 of whom are primary carers – the people who provide the most care.¹

Carers are an integral part of Australia’s health system and are the foundation of our aged, disability, palliative and community care systems. Carers come from a diverse range of socio-economic backgrounds and become carers at various stages in their lifetime.

It has been identified that:
➤ 300,000 carers are under the age of 24²
➤ 150,000 carers are under the age of 18³
➤ Over 1.5 million carers are of prime working age (18-64)⁴
➤ According to the ABS (2008) 31,600 indigenous carers are over the age of 15⁵
➤ 620,000 carers were born outside Australia⁶
➤ 366,700 carers were born in non-English speaking countries⁷
➤ 520,000 carers are over 65 years of age.⁸

The annual replacement value of care provided in 2010 is over $40.9 billion. It is estimated that carers provided 1.32 billion hours of unpaid care in 2010, the productivity loss of which is estimated at $6.5 billion.⁹

On average carers spend approximately 40 hours per week providing care. It is estimated that carers of someone with a mental illness spend on average 104 hours per week in the caring role.¹⁰

ENDNOTES

2. Ibid.
3. Ibid.
4. Ibid.
7. Ibid.

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What is a carer?

Carers come from all walks of life, according to this fact sheet from Carers Victoria.

**You or someone you know may be a carer**

A carer is someone who helps and supports a family member or friend who needs assistance. This may be a frail older person, an adult or child with a disability, a person with a chronic or mental illness or someone recovering after a long illness or accident.

Carers come from all walks of life – all cultures and all religions. Some are only 10 years of age while others are nearing 90. They may be spouses, parents, sons or daughters, siblings, friends, nieces or nephews or neighbours.

Some are ‘full-time’ carers while others balance both a job and caring responsibilities. Most live with the person they care for although some live nearby or are caring from a distance. More carers are women but there are many men who are carers too.

It can be difficult to identify a carer because some don’t use this word to describe themselves – many do not receive a Carer Payment or Carer Allowance from Centrelink. Nevertheless, they are still carers.

**What do carers do?**

The role of each carer is different depending on the needs of the person they care for.

“Once I was acknowledged as a carer I felt better about myself and what I was doing.”

Carers may help with some or all of the following:

- Shopping
- Walking
- Bathing
- Banking
- Sitting and rising
- Dressing
- Housework
- Organising appointments
- Grooming
- Gardening
- Transporting
- Toileting
- Preparing meals
- Reminding
- Putting to bed
- Eating
- Communicating
- Getting up
- Medications
- Therapy.

“Caring for my wife is far more time-consuming than I expected. I’m 24 hours on call.”

Of course there are many things that carers do which are not listed here including comforting, encouraging and reassuring their family member, closely monitoring their safety, helping their family member to maintain as much independence as possible and overseeing their health and wellbeing. It’s very important that carers look after their own health too.

**How and why do people become carers?**

People become carers in different ways. This may happen:

- Gradually – by helping out more and more over time, or
- Suddenly – after a health crisis (for example, a stroke).

It’s not uncommon for carers to feel that they didn’t really have a choice about taking on a caring role. This is particularly so for spouses, who often see caring as a natural extension of their relationship. Many feel it is what they ‘should’ do.

The expectations of family and others can also weigh heavily. Even in large families the responsibility of providing care is often left to one person rather than being shared. As caring can be a challenging and all-consuming role, carers need the support of family and friends.

Many carers say that despite the challenges (for example, tiredness, conflicting emotions, less opportunities to socialise or work and minimal family support) they would do it all again.

Caring can bring a great sense of satisfaction. It may allow carers to prove themselves, strengthen their relationship with the person they care for and gain their appreciation – these can be strong incentives for taking on a caring role.

**When do carers stop being carers?**

In most situations caring does not cease – it simply changes.

Even when caring at home is no longer possible carers may continue this role with their family member in residential care – that is, in low or high level care which used to be called hostels or nursing homes.

“Caring has been left to me – because I live near Dad. I accept this, but would welcome help sometimes.”

**Further information**

- Gradually becoming a carer – information sheet
- Suddenly becoming a carer – information sheet
- Things to consider when taking on a caring role – information sheet

Contact the Carer Advisory Line on 1800 242 636* to request the above information sheets be sent to you – or to find out about other information sheets in this series.

*Free call except from mobile phones. Mobile calls at mobile rates.

‘Surviving the maze’

www.survivingthemaze.org.au

Information sheets for carers and families of older people.

‘Surviving the maze’ is a series of approximately 60 information sheets written specifically for people who are caring for an older family member or friend.

Information Sheet 1 – What is a carer?

Series 1 – Caring for an older person

Updated March 2006. Surviving the Maze, A project of Carers Victoria

www.survivingthemaze.org.au

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www.carersvictoria.org.au

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KEY ISSUES FOR CARERS

Caring families save the Australian community more than $40 billion per year, yet too many carers are in poor health, face financial hardship and social isolation and are not properly supported by services, according to this fact sheet overview from Carers Victoria

WE CANNOT SUPPORT THE CURRENT MODEL OF CARING

As the Australian population ages, we face a number of key dilemmas in relation to caring.

We need more people to provide care but caring involves economic, social and health costs
We need more people in the workforce to sustain our economy and support an ageing population
We need more and better services to support both the people who provide care and the people who need it.

Carers Victoria believes that it is possible to resolve these dilemmas.

We believe that Australia must take a systemic approach that acknowledges the ways in which policies interact and affect the lives of those caring and those being cared for
We must make sure that family carers can pursue what they value in terms of combining care work and paid work, and formal and informal caring
We need policies and systems that give caring families real choice.

CARING NEEDS TO BE VALUED AND RECOGNISED

Caring is common to all families and societies yet, too often, the responsibility falls on individual carers.

We believe that caring should not carry the financial, health and social risks to individuals that it does today
We want Australians to see caring as a valued, normal and expected part of life
We want to find ways in which caring can be shared: between individuals, governments and communities; within families; and between men and women
We want professionals to work in partnership with family carers, to value their expertise and to acknowledge the extensive support they provide.

CARERS NEED FINANCIAL SECURITY

Carers often experience financial hardship. The responsibilities of caring can make it difficult to remain in full-time paid employment and the extra costs relating to care and to disability can be enormous.

Carers need reforms to the income support, taxation and superannuation systems to increase their financial security:

We want to reform the income support and tax system to make paid work more compatible with caring and to make it easier for carers to move into and out of employment

We want adequate income support and government funded superannuation for those who provide long-term high intensity care and have a limited capacity to participate in paid work
We want to ensure that those who care have realistic support with care costs.

CARERS NEED FLEXIBLE WORKPLACES

Many carers of working age find it difficult to balance work and care responsibilities.

In Australia, we value the care of young children and a number of government policies help parents to balance work and family responsibilities. We want similar policy reforms to value and support all forms of caring across our lives.

Carers need reforms to workplace regulation to help them to continue to participate in the workforce:

We want to extend work-life balance reforms, such as the right to request flexible work and the right to unpaid care leave, to all carers
We want businesses to understand the benefits of supporting carers in the workplace and to help them with carer-friendly practices
We want to support workforce participation with affordable, high quality, alternative care arrangements for older people and people with disabilities
We want to develop effective training and affirmative action programs to help carers to re-enter the workforce.

CARERS NEED HIGH QUALITY AND FLEXIBLE SUPPORT SERVICES

Every care situation is different. To support caring families, services must match the needs and expectations of those who are providing care and those who are receiving it.

Carers need reforms to the community care system:

We want services to provide families and individuals with a wide range of options and choices
We want services to be consistently available, accessible, affordable, flexible and of good quality
We want to plug the service gaps and to fund increases in the services that carers really need
We want to invest more in supported accommodation, making sure that people with care needs have access to stable secure housing and helping their families to support them as they move away from family care.

Carers Victoria is the statewide voice for family carers, representing and providing support to carers in the community. To find out more, carers can call the Carer Advisory Line on 1800 242 636, or visit their website www.carersvictoria.org.au

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The rewards and challenges of caring

Taking on a caring role is just like taking on a new job – there will be rewards as well as challenges. Understanding these can help prepare you for the role you are about to take on.

“I had no idea what caring might involve. I just took every hour, day, week and month as it came.”

What are the benefits of caring for a family member?
People who are caring for a family member or friend say there are many rewards including:
➤ A sense of satisfaction helping someone in need
➤ Strengthening the relationship with your family member
➤ Knowing that you have done the best you could
➤ Proving to yourself that you can meet a challenge
➤ Receiving the acknowledgement of family and friends
➤ Feeling appreciation from your family member.

What are the challenges in caring for a family member?

While caring for a family member or friend can be incredibly rewarding, it can also be quite demanding. Depending on the nature of your caring role it may place considerable restrictions on your life.

People who have become carers say that sometimes, caring can:
➤ Be physically draining
➤ Be emotionally taxing
➤ Compromise your own health
➤ Restrict your social life
➤ Reduce your contact with family and friends as some pull away
➤ Take away your freedom and spontaneity, and
➤ Impact on you financially.

“I did not realise how much of my own life would have to be put on hold.”

In some situations caring can become so all-consuming that carers lose their sense of identity – of the person they really are. The challenge is to balance your own needs with those of your family member, so that you look after yourself too.

How to care for your family member and yourself too

One of the main ways to ensure that you are able to continue caring for your family member or friend is to take time out for yourself. Although this may feel like a luxury, it is essential – none of us work 24-hour days, 365 days a year! Here are some suggestions:

Find time for yourself – every day
Try to take time for yourself every day to do something you enjoy. This may be reading the paper, calling a friend or having a coffee in bed. It may be 5 minutes or an hour – importantly it will give you a small break in a day filled with routine.

Have someone to talk to
Find someone to talk to, on the good days as well as the not-so-good days. You could talk to family, friends, other carers or contact the Commonwealth Carer Resource Centre® on 1800 242 636 for support.

Keep healthy
Visit your GP for regular check-ups – don’t put this off. Talk to them about your caring role and how you are feeling.

Keep up your interests
Try to stay involved in some of the things you enjoy – you may even decide to take up a new interest or hobby, something you always wanted to do. This might be writing, building models, painting, photography, music, gym or dance. It will give you something else to think about and something to talk about outside of caring.

Accept a little help
Accepting help is not a sign of failure. Rather it may relieve some of the pressure and help you to keep on caring. Help may be from family, friends or support services – it might be at set days and times or on an as-needed...
The rewards of caring

People who care for a family member or friend say there are many rewards:
➤ The opportunity for personal growth and the development of new skills
➤ Proving to yourself that you can meet new challenges
➤ The satisfaction of knowing you have helped someone who needed you, and done the best you could to improve their quality of life
➤ Strengthening the relationship with the person you care for and knowing how much they appreciate your help
➤ Receiving the acknowledgement of your family and friends.

Challenges of caring

Caring can be very demanding and often restricts the lives of individual carers and their families. Carers SA believes that our society relies too heavily on the care provided by caring families. We advocate for practical reforms that will help protect carers from the problems too often associated with caring.

Financial hardship

➤ 50% of primary carers are on a low income and many find it hard to cover living expenses, save money or build up superannuation
➤ The extra costs of caring can be enormous. Caring families often have to find money for extra expenses like heating and laundry, medicines, disability aids, home modifications, health care and specialised transport.

Health and wellbeing

➤ Caring can be emotionally taxing and physically draining. Carers have the lowest wellbeing of any large group measured by the Australian Unity Wellbeing Index
➤ Carers often ignore their own health and are 40 per cent more likely to suffer from a chronic health condition. Some health problems, like back problems, anxiety and depression, can be directly linked to caring
➤ Many carers are chronically tired and desperately need to refresh with just one night of unbroken sleep, a day off or an extended period with no caring responsibilities.

Social isolation and relationships

➤ Many carers feel isolated, missing the social opportunities associated with work, recreation and leisure activities
➤ The demands of caring can leave little time for other family members or friends
➤ Carers often have to deal with strong emotions, like anger, guilt, grief and distress, that can spill into other relationships and cause conflict and frustration.

Disadvantage

➤ Many carers miss out on important life opportunities, particularly for paid work, a career and education
➤ Caring can take the freedom and spontaneity out of life
➤ Caring can have a life-long impact on life opportunities.

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This fact sheet was prepared in collaboration between the National Rural Health Alliance and Carers Australia and draws on the findings of a recent report, *The Tyranny of Distance? Carers in Regional and Remote Australia*, prepared for Carers Australia by the Australian Institute of Family Studies.

**GEOGRAPHIC SPREAD**

According to the 2006 Census, unpaid carers make up 11.2% of the population across Australia. Regional differences are not large (see Table below).

<table>
<thead>
<tr>
<th>Region</th>
<th>% pop. who were carers</th>
<th>% carers who were indigenous</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major cities</td>
<td>11.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Inner regional</td>
<td>12.1</td>
<td>2.2</td>
</tr>
<tr>
<td>Outer regional</td>
<td>11.2</td>
<td>4.6</td>
</tr>
<tr>
<td>Remote</td>
<td>9.0</td>
<td>2.5</td>
</tr>
<tr>
<td>Very remote</td>
<td>9.1</td>
<td>46.8</td>
</tr>
<tr>
<td>Australia</td>
<td>11.2</td>
<td></td>
</tr>
</tbody>
</table>

However, there are carer ‘hot spots’ in a number of Remote and Very Remote areas in NT, WA and SA associated with a high proportion of the caring population in certain statistical local areas being indigenous.

In Very Remote areas a greater proportion of carers are aged 24 years or less and there are far fewer carers aged 65 years or more than in other regions.

### REGIONAL PROPORTION OF CARERS BY AGE GROUP

<table>
<thead>
<tr>
<th>Region</th>
<th>% carers by age group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>15-24 years</td>
</tr>
<tr>
<td>Major cities</td>
<td>7.7</td>
</tr>
<tr>
<td>Inner regional</td>
<td>6.9</td>
</tr>
<tr>
<td>Outer regional</td>
<td>7.2</td>
</tr>
<tr>
<td>Remote</td>
<td>8.3</td>
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<tr>
<td>Very remote</td>
<td>15.7</td>
</tr>
<tr>
<td>Australia</td>
<td>7.6</td>
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</tbody>
</table>

**CARERS’ HEALTH AND SOCIAL INCLUSION**

Wherever they live, carers are slightly more likely to self-report fair or poor health than people without caring responsibilities, rather than good, very good or excellent health. The gap is greatest for people living in Outer Regional and Remote areas of Australia where 22.1% of carers report fair or poor health compared with 17.8% of non-carers in the same regions and 18.0% of carers in Major Cities.

Carers living in Outer Regional and Remote areas experience higher rates of disability or a long-term health condition (20%) compared with non-carers in the same regions (12.3%) and carers in Major Cities (14.3%).

Carers, particularly in non-Metropolitan areas, report having strong social networks for information and advice. Both carers and non-carers in Outer Regional and Remote areas are more likely to personally know someone they could ask for information and advice (84.2% and 72.6% respectively) than carers and non-carers in Major Cities (77.7% and 68.8% respectively).

Almost 2 million carers are of workforce age, but many leave the workforce, reduce the hours they work, or work below their skill capacity because of their caring responsibilities. Carers living in Outer Regional or Remote areas have significantly lower rates of employment (70.3%) than non-carers in the same areas (76.6%) or in Major Cities (77.9%).

In addition, carers living in all parts of Australia are more likely to be living in a jobless household which means they are more likely to experience financial hardship. The greatest differences are evident in Outer Regional and Remote areas where 21.4% of carers live in jobless households compared with 12.2% of non-carers.
ACCESS TO SERVICES AND SUPPORT FOR CARERS IN RURAL AND REMOTE AUSTRALIA

Overall, 30.4% of carers in Australia report having problems accessing doctors or employment services, telecommunications services, Centrelink, banks, disability services, the Family Assistance Office or Medicare, compared with 25.3% of those without caring responsibilities.

Outside Major Cities and Inner Regional areas both carers and non-carers are much more likely to report having difficulties in accessing services, with the proportion of carers higher.

Distance to or lack of adequate services in the area is the major difficulty reported. Affordability was a difficulty for 11.2% of carers in Outer Regional and Remote areas compared with 7.3% of carers in Major Cities and 7.8% of non-carers in Outer Regional and Remote areas.

Young carers are at high risk of not participating in education or paid work ... they are also at risk of socioeconomic disadvantage, isolation, low levels of health and wellbeing and impaired psychosocial development.

In addition, carers reported that difficulties in understanding or being understood by service providers contributed to the challenge of accessing services, particularly in Outer Regional and Remote areas.

Carers living outside Major Cities were slightly more likely to rely on health, legal or financial professionals in times of crisis than carers in Major Cities. This is problematic given the difficulties rural carers report in accessing such services.

SUPPORT FOR CARERS IN RURAL AND REMOTE AUSTRALIA

The contribution to society that carers in Australia give has now been formally recognised through the Carer Recognition Act 2010 passed by Parliament in November 2010.

Centrelink provides financial assistance and services to carers in the community. Carer Payment is an income support payment for people who, because of the demands of caring for a relative or friend, are unable to support themselves through paid employment. Carer Payment has an income and assets test and is paid at the same rate as other social security pensions.

The Carer Allowance is a supplementary payment available to people who provide daily care and attention in a private home to a person who has a disability, severe medical condition or is frail and aged. It is not taxable or income and assets tested and it can be paid in addition to wages and income support payments such as the Age Pension and Carer Payment.

More information is available from Centrelink on 13 27 17 or www.centrelink.gov.au/internet/internet.nsf/individuals/carer_index.htm

YOUNG CARERS

There are 380,000 people under the age of 26 providing care to a family member in Australia, including 170,600 under the age of 18.

Young carers are at high risk of not participating in education or paid work. For this and other reasons they are at risk of socioeconomic disadvantage, isolation, low levels of health and wellbeing and impaired psychosocial development.

37 per cent of young carers aged between 15-24 live in rural or remote Australia.

Visit www.youngcarers.net.au for information and support for young carers.

Respite care includes a range of short-term care options to provide temporary relief for people caring for family members who might otherwise require permanent placement in a facility outside the home.

For example, Frontier Services provides aged care and respite services to outback Australia across 85 per cent of the continent, including a mobile van (affectionately called ‘Troopy’) that moves from one community to another to provide local respite care sessions.

The National Respite for Carers Program supports carers of older people and those with disabilities to take time out from their caring role. Information about respite services in your local area can be obtained by phoning a Commonwealth Respite and Carelink Centre on Freecall™ 1800 052 222® during business hours or, for emergency respite support outside standard business hours, Freecall™ 1800 059 059®.

Carers Australia and the network of Carers’ Associations in each State and Territory aim to improve the lives of carers. Carers also have access to short-term professional counselling and assistance to manage issues such as stress, loss and grief through the Carers Advisory and Counselling Service on the national Freecall™ number 1800 242 636® or visit www.carersaustralia.com.au

®Calls from mobile phones are charged at applicable rates.

ENDNOTES

1. The high levels of employment relate to the categories of labour force status used in the Australian Bureau of Statistics (ABS) General Social Survey (GSS) 2006: employed (usually works one or more hours per week); unemployed and not in the labour force.

Fact Sheet 22 – Carers in the bush, October 2010
National Rural Health Alliance Inc.
www.ruralhealth.org.au
Women carers face a lifetime of health and economic consequences

In Australia, primary carers are most often women. These women can pay a high price in terms of health and financial wellbeing for taking on this role, observes this report from the Working Carers Gateway.

The Commonwealth Financial Planning (CFP) Women Carers in Financial Stress Report is the first to examine the lifetime financial consequences of caring on Australia’s predominantly female carer population.

A summary of the report’s findings will be presented this month at the National Conference on Caring 2009, being held at the Royal Pines Resort, Gold Coast, on March 9 and 10, by Dr Binod Nepal, PhD, a research fellow at the University of Canberra’s National Centre for Social and Economic Modelling, who was a co-author of the report.

Tim Gunning, CFP general manager, said Australia’s 2.6 million unpaid carers provide services estimated at more than $30.5 billion annually, yet many remain economically and socially disadvantaged.

“The CFP Women Carers Report shows informal carers have lower workforce participation rates and reduced healthy lifespan, fuelling a reduction in household incomes and retirement savings,” he said.

“I believe this research will significantly raise awareness on the wellbeing of carers and identify actions to reduce the risk of unnecessary financial stress on these members of the community.”

The key issues raised in the report highlight that home-based care provided by family members is the most common form of caring for people with disabilities in Australia. However, it is becoming increasingly evident that this model of care is generating enormous health and financial consequences for informal carers.

Carers are experiencing high stress levels, low sense of wellbeing and poor health. A key contributor to this is the high level of financial stress they face. There are many factors contributing to carers and their families having low household incomes.

The main reason is that taking on an informal carer role has a significant impact on an individual’s ability to work. Many carers leave paid employment either permanently or on a part-time basis to become carers.

Because primary carers are more likely to be women than men, women are more likely to ‘pay the price’ of being a carer.

Spending all or a significant proportion of one’s working years out of the workforce also means that there is limited opportunity to invest towards retirement through superannuation, and with high household expenditure levels relative to income, there is little opportunity for household savings.

With negligible or no superannuation, carers will have to depend on the aged pension provided by the government to support their needs in their retirement years, the report found.

Because primary carers are more likely to be women than men, women are more likely to ‘pay the price’ of being a carer.

In Australia, primary carers are most often women. Two groups of primary carers who represent a large proportion of informal carers are women caring for a child with a disability and women caring for a male partner with a disability. These two groups of women carers pay a high price in terms of their health and financial wellbeing for taking on a primary carer role.

As shown in this study, the impact of being a primary carer is significant and extends to the rest of the primary carer’s life – they experience a shorter period of good health over their working years; they are less able to participate in paid employment; receive lower income during their working years; and are less able to invest towards retirement.

As such, government policy addressing how to better support the needs of carers needs to focus on strategies and measures that will:

1. Enable carers to maintain good health over their lifetime
2. Reduce financial stress through facilitating greater participation in paid work or increased government financial assistance and income support, and
3. Provide carers with a means to contribute to a superannuation scheme that will help provide for them in their retirement.

A quick summary of some of the report’s major findings:

➤ Two to four times the proportion of women primary carers report their health as being only fair or

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Issues in Society | Volume 342

Carers: Ageing and Disability
poor compared with other women of a similar age

➤ The impact of caring on the health of carers increases with their age

➤ Women primary carers are likely to be in a healthy state for a shorter period of their life than other women

➤ Self-reported health status is positively associated with household income. Primary carers experience lower levels of self-reported health status compared to other women

➤ The majority of female primary carers aged 30 to 64 years are out of the paid labour force

➤ Primary carers spend fewer hours in paid jobs than do other women

➤ Mothers who are primary carers of a child with a disability are likely to earn over their working life – depending on their level of education – between a quarter and half the income of women sharing the same characteristics but who are not primary carers

➤ While mothers who are primary carers of a child with a disability receive more in government benefits than other women, these payments do not compensate fully for the income they forgo from paid work

➤ The superannuation likely to be available to 30-year-old women who are primary carers caring for a child with a disability when they reach 65 years of age will be negligible for many, and insufficient to provide an adequate retirement income for most

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**Women primary carers are likely to be in a healthy state for a shorter period of their life than other women.**

➤ Women who are aged 50 years old taking on a primary carer role for a partner with a disability and who are able to maintain some paid work would expect to earn approximately 80 per cent of the accumulated income that would be earned by other women without carer responsibilities

➤ Access to government benefits for this group of carers goes a considerable way in compensating for loss of income through caring roles

➤ There is over a two-fold difference in the superannuation that a 50-year-old woman primary carer (of a male partner who is no longer able to work because of her caring role and who has secondary school qualifications only) can expect to access at 65 years of age, compared to women who have post-secondary schooling, who continue to work up to retirement at 65 years of age, and who do not have the same caring responsibilities.

* The study was conducted by NATSEM, the National Centre for Social and Economic Modelling, a major research centre within the University of Canberra.

Working Carers Gateway, 3 March 2009
www.workingcarers.org.au

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An increasing number of older men are becoming their partner’s carer, but research suggests they need more practical support, according to this *ABC Health and Wellbeing* report by Genelle Weule.

This year the first wave of baby boomers turns 65. While most will look forward to spending their winter years playing golf, exploring the countryside in their camper trailer or spending the kids’ inheritance. Some will travel another path.

By 2050 it’s estimated that 75,000 baby boomers will have dementia. Many others will be caring for someone with dementia, and a growing proportion of these carers will be men over the age of 65.

By 2050 it’s estimated that 75,000 baby boomers will have dementia and many others will be caring for someone with dementia.

Already men over 65 are more likely to be caring for a partner with dementia than women of the same age.

But we know little about the experiences of older husbands who provide at-home care for their wives with dementia, says Associate Professor Peter Brown from Charles Darwin University.

“There is an increasing number of males who are providing support for spouses in particular. These tend to be older husbands,” says Brown.

“The average age of males is increasing and the average number of men moving into the mid-old and old-old group is increasing significantly as well, so more males ... are available to provide care.”

To gain an insight into the specific needs men had as carers, Brown interviewed 17 older male carers over 65, then surveyed a further 71 older male carers about their approach to care giving. The survey also asked questions about their level of family support, access to professional support services, and the husbands’ level of independent living skills prior to their wives’ illness.

A vast majority of the men reported performing between 80 to 100 per cent of their wives’ care.

**CARERS AT RISK**

At least 40 per cent of the men surveyed experienced symptoms of depression and 23 per cent were depressed, found Brown.

“One of the central findings is the need for health professionals to identify males who are at risk of breakdown, being overwhelmed, institutionalising their wives too early, not being able to manage,” says Brown.

Brown found that those older male carers who were more likely to experience depression perceived caregiving as being like a job, avoided coming to terms with their wives’ illness and its consequences for them as carers, and had difficulty contacting relatives and friends for help.

“Males tended to ... value efficiency and organisation and the supervision sort of approach to care that they would’ve utilised in a work situation,” says Brown.

“They found it more difficult to cope with the more intimate aspects of caregiving such as changing incontinence pads or showering their wives.”

“Males were less likely to acknowledge that they were experiencing difficulty in relation to these roles,” he says.

Some husbands found it very difficult coming to grips with the changes in their wives’ condition.

“Some carers responded when they got the diagnosis ‘thank God it’s not cancer’, which indicated to me they didn’t have really much understanding of what was happening.”

While some men had the support of a family member, usually a daughter, many were the primary caregiver and family lived some distance away. Some men were further isolated because their families did not understand the nature of dementia, and in some cases family members resented their father making decisions for their mother.

“Families ... didn’t always have a full understanding of dementia, what it actually meant and its prognosis. And they didn’t always have a good understanding of the level of burden that their fathers were experiencing providing care,” says Brown.

**PRACTICAL SUPPORT**

Many of the men Brown interviewed used services, such as day care and support groups, for example Alzheimer’s Australia. But many still reported that they needed more practical support, such as night care, weekend respite,
assistance with bathing, help with home maintenance tasks and someone to sit with wives while they attended to other responsibilities.

And it is practical help that men need more of, says Anthony Brown, resource officer at the Men’s Health Resource Information Centre at the University of Western Sydney.

“Men are often looking for practical suggestions and practical support – not that women aren’t – but men value groups and information that tells them how they can do the caring job better,” says Brown.

“Men tend to see the caring role as a job, a task that needs to be done and that’s how they get through the day and help the person they’re caring for.”

“I think it would be very dangerous and ultimately unproductive to shift how men see the caring role,” says Brown, adding that it would be better to provide support that meets men’s need for practical information.

So should you be faced with caring for someone with dementia – or supporting someone who is a carer – what can you do?

The men interviewed by Peter Brown found the following strategies helpful:

➤ Maintain your own outside interests and hobbies, organise back-up care so you can do so
➤ Use respite and day care – many of the men found day care particularly useful
➤ Make financial and legal plans early on, for example, organise Power of Attorney
➤ Use support groups, such as the Alzheimer’s Association
➤ Ask family members for assistance, this might include regular visits, phone calls, or bringing over a cooked meal
➤ Maintain a sense of humour
➤ Let go, accept you are the carer of someone who needs caring for, that this person has a disease that is incurable and you will provide care for as long as you can
➤ Establish a routine. This is useful for both the person with dementia and the carer
➤ Encourage the person needing care to do what they can still do, for example, they may not be able to make a cup of tea, but can still be involved in getting cups out of cupboard.

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Young carers are people under the age of 26 who provide care in a family affected by illness, disability, mental health and/or drug or alcohol issues of one or more family members or friends. In Australia there are approximately 380,000 young carers under the age of 26 and of these it is estimated that 170,600 are under the age of 18.

Young carers provide a wide range of practical and emotional assistance to those for whom they care including:

➤ Accompanying the person cared for to medical appointments
➤ Assisting the person they care for with dressing, bathing, toileting and mobility
➤ Administering or reminding about medication
➤ Providing social support to the care recipient
➤ Providing support during periods of increased emotional or physical stress
➤ Buying groceries, cooking, cleaning, handling household finances
➤ Advocacy and negotiation with service providers.

At least one in ten children in Australia has some level of care responsibility in their home. This equates to there being, on average, two or three young carers in every classroom in Australia.
Carers’ Week is a time in which we can bring the spotlight to bear on an issue that should continue to shame policymakers throughout Australia – the way in which those who care for some of the most vulnerable in our society are increasingly isolated and forgotten.

Australia’s 470,000 carers provide services that would otherwise cost federal, state and territory governments $40 billion a year. Yet when budget time comes around each May, all Australia’s carers can hope for is that a few extra crumbs might fall off the table.

Amongst this large group of Australians is a sub-group that is especially vulnerable. There are 28,000 Australians over the age of 65 years who are the primary carer for an adult child with a disability.

As with other carers, they are exhausted, isolated, stressed, suffering ill-health and struggling to navigate through a complex and under-resourced service system. Added to the woes of Australia’s older parent carers is the ongoing fear they have about the future of their son or daughter after they are too frail to care for them any longer or pass away.

ANGLICARE Sydney has today released new research that captures the experiences of these older parent carers and the enormous challenges they face. The findings are based on nearly 300 entry surveys of carers coming into ANGLICARE’s five Support Coordination Programs in Sydney.

Nearly all were over the age of 65, with one in five surveyed older than 80 years. Over 80 per cent were female and nearly half of these were widows. Nearly all the carers lived full-time with the person they looked after – a 24/7 caring role. In most cases, the main disability of the son or daughter was intellectual.

More than a third had been in their caring role for more than 40 years.

The study found that older parent carers:
➤ Experience significant levels of ongoing stress and often have compromised personal health – 25 per cent said they had poor health
➤ Need more help in planning for future care of their son or daughter – 80 per cent were anxious about their child’s future care
➤ Need better information about where to get help from services
➤ Need more support to manage challenging behaviours of those they care for, and
➤ May experience significant social isolation as a result of having such an intense caring role.

That this is occurring in a city where we can turf the Harbour Bridge for a picnic is a national shame. These aren’t people looking for handouts. They are hardworking, they are resilient and they are stoic. But as they get older, it’s just getting harder. Harder to find the information about what is available for them; harder to access flexible respite options; and harder to even get out of the house to take care of the shopping or just have some time to themselves. Upon entry to ANGLICARE’s program, only 54 per cent of carers indicated that they had accessed respite in the previous 12 months.

This is simply not acceptable. We need more in-home respite, delivered with a focus on the clients’ experience of service and which takes into account carers’ needs.

We need more funding for ageing parent carer support programs which provide holistic case management.

We need better transition planning to help plan for long-term care. For example, blended accommodation options where the older parent can live in a care service with their son or daughter in the same general service or nearby.

We need government to ensure that there are long-term supported accommodation options available for people with a disability.

The provision of these additional services would be a fraction of the value of the care these older Australians have been providing for decades.

We can and must do better.

Peter Kell is the CEO of ANGLICARE Sydney, one of Australia’s largest community service organisations.

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Older parent carers: exhausted, isolated and forgotten

More funding, better planning and support services are required to support these older Australians who have been providing care for decades. We can and must do better, urges Peter Kell

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National Carer Strategy launch

An overview of the federal government's recognition and support for Australia's carers can be found in this announcement from Jenny Macklin and Nicola Roxon

Australia’s 2.6 million carers will receive improved recognition and support following the launch of the federal Government’s National Carer Strategy in Victoria

The Minister for Families, Housing, Community Services and Indigenous Affairs, Jenny Macklin, the Minister for Health and Ageing, Nicola Roxon, and the Parliamentary Secretary for Disabilities and Carers, Senator Jan McLucas today visited Carers Victoria in Footscray to launch the Strategy, which includes $60 million in new funding over the next four years.

The Strategy delivers on the Australian Government’s commitment to better respond to the needs of carers, and helps to ensure carers have the opportunity to take part in all aspects of society, including the chance to participate fully in work, community and family life.

New funding delivered under the National Carer Strategy includes:

➤ $42.6 million to extend automatic eligibility for the Carer Allowance (child) for around 2,200 carers of children with Type 1 Diabetes who are aged between 10 and 16 years

➤ $10.3 million to continue the Carer Adjustment Payment, a one-off payment for families who, following a catastrophic event involving a child aged 0-6 years, need additional support to cater to the needs of their child

➤ $2.9 million to improve access to the Carer Supplement for carers who are working when the Supplement is paid in July each year, which will help carers to maintain paid employment

➤ $2.1 million to ensure fairer access to Bereavement Payment, which will provide some assistance to carers receiving Carer Allowance and an income support payment at the difficult time following the death of the person they are caring for

➤ $1.6 million for a national and targeted campaign to raise awareness of the role of carers.

The National Carer Strategy will help to ensure carers have the same rights, choices and opportunities as other Australians. It also aims to help build a society which genuinely values and respects carers.

The Strategy sets out how governments, business, health and community professionals and the wider community will work cooperatively together to achieve this vision. It is supported by the Australian Government and all State and Territory Governments.

Through their hard work and sacrifice, carers greatly improve the quality of life of millions of people across the nation.

Through their hard work and sacrifice, carers greatly improve the quality of life of millions of people across the nation. However, too often this work goes unnoticed. The National Carer Strategy recognises the invaluable contribution of carers to the Australian community.

This week, the Australian Government received the Productivity Commission’s final report into a long-term disability care and support scheme and will now carefully consider the report.

The National Carer Strategy builds on the work the Government has already done to improve the lives of carers and the people they care for.

This includes:

➤ The National Disability Strategy, a ten-year reform plan to address the barriers faced by Australians with disability, which was endorsed earlier this year by the Council of Australian Governments (COAG)

➤ Australia’s first national Carer Recognition legislation

➤ Historic increases to the Carer Payment delivered in 2009, now worth $128 extra per fortnight for singles on the maximum rate and $116 extra for couples combined on the maximum rate

➤ A permanent $600 annual Carers Supplement

➤ Simpler and fairer assessment process for Carer Payment (child) and Carer Allowance (child)

➤ Doubling Commonwealth funding under the National Disability Agreement, and higher annual indexation, for more and better specialist disability services

➤ A $54.3 million boost to mental health respite services in this year’s Budget

➤ More supported accommodation – in 2008, $100 million to deliver up to 313 new places, and this year a further $60 million to deliver an extra 150 community-based supported accommodation or respite places for people with disability.

The National Carer Strategy has been developed in consultation with carers, state and territory governments, service providers and peak organisations.

We thank all those people who took the time to attend consultation workshops or provide written submissions to inform the development of the Strategy.

For more information about the National Carer Strategy, visit www.fahcsia.gov.au

Joint media release, 3 August 2011
Senator Jan McLucas, Parliamentary Secretary for Disabilities and Carers and Nicola Roxon MP, Minister for Health and Ageing
www.fahcsia.gov.au

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The development and implementation of the National Carer Strategy is the Australian Government’s recognition of the invaluable contribution of carers to the Australian community. It outlines how this contribution can be valued, supported and shared.

The National Carer Strategy builds on what the Australian Government already provides for carers and complements reforms to improve supports provided through the aged care, disability, mental health, primary health care, hospital, and community care systems.

The National Carer Strategy gives effect to the principles of the Carer Recognition Act 2010.

It sits alongside and complements the National Disability Strategy, a 10-year plan for improving the lives of Australians with disability, their families and carers.

Our vision is to ensure that society values and respects carers and to ensure they have rights, choices, opportunities and capabilities to participate in economic, social and community life.

The National Carer Strategy sets out how governments, business, health and community professionals as well as the wider community will work cooperatively together to achieve this vision. The aim is to provide carers with services and supports that are coordinated, flexible, appropriate, affordable, inclusive and sustainable.

The National Carer Strategy contains six priority areas for action:

➤ Recognition and respect
➤ Information and access
➤ Economic security
➤ Services for carers
➤ Education and training
➤ Health and wellbeing.

Under each of these priority areas, policy directions and areas for action in the shorter term have been identified.

State and territory governments have welcomed the Strategy’s vision, aim and priority areas and have committed to identifying strategies and activities that complement the National Carer Strategy.

The aim is to provide carers with services and supports that are coordinated, flexible, appropriate, affordable, inclusive and sustainable.

The Australian Government is making major investments to support carers, including:

➤ $7.6 billion between 1 January 2009 and 30 June 2015 provided to state and territory governments to increase and improve specialist disability services provided under the National Disability Agreement
➤ $2.2 billion over 5 years to drive fundamental reform in Australia’s mental health system, including:
  – A $54.3 million boost to mental health respite services,
to help carers have a break or undertake education or training.

- $61 million for Family Mental Health Support Services to provide improved support and strengthen families affected by mental illness

➤➤ $4.26 million over 4 years to extend automatic eligibility for Carer Allowance (child) for carers of children with Type 1 Diabetes aged between 10 and 16 years

➤➤ $10.3 million over 4 years to continue Carer Adjustment Payment, a one-off payment to families where, following a catastrophic event involving a young child aged 0 to 6 years, the family is going through a period of significant adjustment as a result of the care needs of the child

➤➤ $2.9 million over 4 years to ensure fairer access to the Carer Supplement

➤➤ $2.1 million over 4 years to ensure fairer access to Bereavement Payment

➤➤ $1.6 million over 2 years to fund a national and targeted campaign to raise public awareness of the role and contribution of carers.

In addition, the Australian Government:

➤➤ Has extended the Demonstration Day Respite Pilot for a further 12 months and will evaluate the effectiveness

of respite options for supporting carers who want to balance paid work with informal care

➤➤ Will consult with stakeholders about expanding the right to request flexible working arrangements under the Fair Work Act 2009 to employees caring for older Australians and those caring for a person with a serious long-term illness or disability

➤➤ Will provide $1 million to hold a young carer festival in each state and territory.

The National Carer Strategy is the outcome of consultations with carers, state and territory governments, service providers and peak bodies. The paper Towards a National Carer Strategy formed the basis of these discussions – a summary of these consultations is in Section 9 of the National Carer Strategy.

Chapter 2 – Summary, National Carer Strategy
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CARERS IN AUSTRALIA

This National Carer Strategy extract underscores the diversity of carers in the community

It is difficult to make generalisations about carers in Australia because each caring situation is unique. No two people – those providing the care or those requiring care – are the same. Carers reflect the diversity in our community – carers are all different ages, male and female, who live in different locations, and come from different cultural and socioeconomic groups.

What we do know is that one third of Australia’s 2.6 million carers are primary carers – they provide most of the informal help for a person with disability or a person aged 60 years and over. Over two-thirds of primary carers are women and most care for a close relative such as a partner, parent or child.¹

The one thing all carers and the people they care for have in common is being in a care relationship. Care relationships can be long term, such as caring for a person with lifelong disability or chronic condition such as dementia, or short term, such as caring for a person with a temporary medical condition. Care relationships can also be episodic, such as caring for a person with mental illness.

Care relationships vary according to the needs of the person(s) being cared for, the carer’s own individual needs, and changing life circumstances.

“Caring is done by individuals who bring their life experiences, values, beliefs, attitudes, expectations, coping mechanisms, economic resources, culture and gender to caring. Caring is therefore shaped by the environment in which it occurs and by an individual’s history. As a result, every caring situation will be unique and every carer will care differently.”²

It is these care relationships, and the health and wellbeing of each person in the relationship that needs to be supported and sustained. The challenge for the Australian Government is to develop strategies, policies and programs that are broad and flexible enough to provide this support in each unique situation and meet individual needs.

It is also important to remember that many people do not formally identify as carers despite the extensive support and assistance they provide to a family member or friend. Estimates of the numbers of carers are therefore likely to be smaller than the actual number of people providing informal care and support in the community.

Chapter 3 – Carers in Australia, National Carer Strategy
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The place of the National Carer Strategy

THIS ARTICLE OUTLINES HOW THE STRATEGY FORMS PART OF THE LARGER SOCIAL INCLUSION AGENDA OF THE AUSTRALIAN GOVERNMENT

The National Carer Strategy does not sit in isolation. It is an integral part of the Australian Government’s broader social inclusion agenda and it sits alongside and complements the National Disability Strategy. In conjunction with the Carer Recognition Act 2010 it forms part of the Australian Government’s National Carer Recognition Framework.

Social Inclusion Statement

The Australian Government’s Social Inclusion Statement, A Stronger Fairer Australia, sets out Government’s plan to ensure every Australian has the capabilities, opportunities, responsibilities and resources to learn, work, connect with others and have a say.

Improving outcomes for people living with disability or mental illness, and their families and carers is a key priority of the Statement. The Australian Government recognises that each of these groups may need additional support to participate fully in the economic and social life of the community.

The Social Inclusion Statement recognises that a number of groups – older carers, young carers, indigenous carers, carers from culturally and linguistically diverse backgrounds, carers living in rural, regional and remote areas – face particular challenges. It recognises that additional strategies may be required to ensure these carers have the same opportunities as other Australians to participate in the economy and the community.

National Disability Strategy

Developed under the auspices of the Council of Australian Governments, the National Disability Strategy sets out a ten-year plan for improving the lives of Australians with disability, their families and carers.

The purpose of the National Disability Strategy is to guide the development of policies, programs and services to better meet the needs of people with disability, their families and carers. The National Disability Strategy outlines the steps that will need to be taken to ensure its vision of an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens is achieved. It aims to have an impact not simply on disability specific programs and services but the development of all government policies and programs – because all policies and programs have an impact on people with disability, their families and carers.

The National Carer Recognition Framework

During 2008 and 2009 the House of Representatives Standing Committee on Family, Community, Housing and Youth conducted an inquiry into the experience of carers.

It investigated how the Australian Government could better respond to their needs, and how the role and contribution of carers could be better recognised in the community.


The Carer Recognition Act 2010 formally acknowledges the significant contribution that carers make to the Australian community. It aims to ensure that the needs of carers are considered in the development, implementation and evaluation of Australian Government policies, programs and services that directly affect them or the person they care for.

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THE AUSTRALIAN GOVERNMENT’S SOCIAL INCLUSION STATEMENT: ‘A STRONGER FAIRER AUSTRALIA’

National Carer Recognition Framework

Carer Recognition Act 2010

Definition of carer
Carers are people who provide personal care, support and assistance to people with a disability, medical condition (including terminal or chronic illness) mental illness, or frailty due to age.

The Statement for Australia’s Carers
Ten core principles to guide the framework:
1. All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, indigenous heritage, cultural or linguistic differences, socioeconomic status or locality.
2. Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential.
3. The valuable social and economic contribution that carers make should be recognised and supported.
4. Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.
5. Carers should be acknowledged as individuals with their own needs within and beyond the caring role.
6. The relationship between carers and the persons for whom they care should be recognised and respected.
7. Carers should be regarded as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.
8. Carers should be treated with dignity and respect.
9. Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.
10. Support for carers should be timely, responsive, appropriate and accessible.

Obligations
Obligations on Australian Public Service agencies and service providers.

Vision
Carers in Australia are valued and respected by society. They have rights, choices, opportunities and capabilities to participate in economic, social and community life.

Aim
To respond to the diverse and changing needs of carers with services and supports that are coordinated, flexible, appropriate, affordable, inclusive and sustainable.

Priority areas

Recognition and respect
Information and access
Economic security
Services for carers
Education and training
Health and wellbeing

Chapter 4 – Carers in Australia, National Carer Strategy
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INTRODUCTION

The National Carer Strategy comprises one part of the National Carer Recognition Framework. The other part is the Carer Recognition Act 2010. The Framework was developed in response to an inquiry conducted by the House of Representatives Standing Committee on Family, Community, Housing and Youth in 2008-09. Carers Australia was contracted to undertake consultations and submissions were invited in December 2010. Consultations included over 300 carers around the country. The Strategy has $60 million funding associated with it through the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), of which $57.9 million is earmarked for carer payments through Centrelink.

The Strategy identifies six priority areas for action:

- Recognition and respect
- Information and access
- Economic security
- Services for carers
- Education and training
- Health and wellbeing.

There are policy directions identified under each priority area. Some fall under other initiatives the government has embarked on, including: the National Disability Strategy, the National Health Reform Agreement, and the National Mental Health Reform package. Some of the existing and planned initiatives identified in the National Carer Strategy were announced under the above reforms. The summary below includes only new programs not announced as part of other initiatives.

ACTIONS IN PRIORITY AREAS

1. Recognition and respect
   - $1.6 million for a national awareness campaign about the role of carers and to encourage carers to seek support
   - Review legislation and policy to improve recognition of carers
   - Work with service providers to improve services to people who do not recognise themselves as carers
   - Promote service models (in health, aged care, and disability services) that recognise the role of carers.

2. Information and access
   - Address information needs of carers in special needs groups such as Aboriginal and Torres Strait Islander, carers living in rural and remote areas, and younger carers
   - Educate agencies that are the first point of contact for carers on how to link carers with relevant and appropriate information.

3. Economic security
   - Change eligibility for carer payments, including the Carer Supplement for carers in paid employment, Bereavement Payments, and Carer Adjustment Payment
to those who, access to the Carer Allowance to parents of children aged between 10 and 16 years with Type 1 Diabetes, and increase of the Carer Adjustment Payment – total $57.9 million over 4 years

➤ Extend the Day Respite Pilot to allow further evaluation of the effect of day respite options for carers in paid employment

➤ Investigate the possibility of extending rights to request flexible working arrangements under the *Fair Work Act* 2009 to carers of older people, adults with disability, or people with long-term illness.

4. Services for carers

➤ Test and support consumer-directed support for carers

➤ Improve carer support programs to increase access to timely respite services

➤ Improve data collection models and increasing research about carers.

5. Education and training

➤ Identify gaps in services that support carers to gain the skills they need to commence, maintain and cease their caring role

➤ Develop greater flexibility in education services to support those who do not identify as carers

➤ Increase awareness amongst education providers of the impact of caring responsibilities on students.

6. Health and wellbeing

➤ Make carers a priority in the Access to Allied Psychological Services program which enables general practitioners to refer patients to allied health professionals for psychological services

➤ Fund young carer festivals in each state to provide younger carers with opportunities for respite, socialising, and recreation

➤ Make locally-based peer support groups a priority within existing community grants programs

➤ Amend the scope of existing respite programs for more flexibility.

**IMPLEMENTATION AND MONITORING**

Responsibility for implementation lies with the Commonwealth Carers Forum, which includes Commonwealth Government agencies who have responsibilities for carers. The Commonwealth will work with the National People with Disability and Carers Council, carer representative organisations, and state and territory governments to implement the Strategy. The Commonwealth Carers Forum will report annually to the Council of Australian Governments (COAG).

**COMMENTS**

Commitments under this Strategy are largely uncosted, and opportunities for the community sector to engage in the process of implementation are limited. There are few new initiatives announced under the Strategy, and the largest item of expenditure, increased eligibility for the Carers Allowance for carers of children with Type 1 Diabetes, is the outcome of a specific review of eligibility criteria for the Carers Allowance, not consultations around the National Carer Strategy. The possibility of new services, such as consumer-directed support for carers, are exciting, but are not backed by funding or specific arrangements. Some initiatives, such as increased rights to request flexible work arrangements for carers of adults with disability and older people, are likely to be highly beneficial if they are implemented. However, some of the initiatives allow scope for advocacy, with the Commonwealth Government having made commitments to several actions.

However, the agencies with specific responsibilities to implement and monitor this strategy are not identified except at a very general level, and timeframes for achieving outcomes are not specified. The extent to which state and territory governments will commit to the Strategy is unclear, and they do not appear to have been party to the commitments made under the Strategy. Given that carers remain a joint responsibility between federal and state and territory governments, a national strategy requires the commitment of states and territories to be effective.

This Strategy also does not reference the recent Senate inquiry report on people with disability who are ageing, which also proposes a number of initiatives for carers of people with disability. Issues identified in that report, including legal and financial issues, are not mentioned in the Strategy. The timing of the Strategy’s release, shortly before the Productivity Commission Reports on *Caring for Older Australians* and *Disability Care and Support*, seems to have limited its scope and the capacity for it to offer complementary arrangements, and new funding, for carers of older people and people with disability.

The *Caring for Older Australians* report recommends that new Carer Support Centres be set up to coordinate respite, and provide training, counselling and advocacy to carers of older people and people with disability. The substantial nature of the services recommended have not been included in the strategy, and presumably they will not be monitored or implemented in the same way as the reforms recommended by the Productivity Commission. This will tend to undermine the Strategy’s aim to improve data collection and coordination.


NC OSS Summary: National Carer Strategy
Department of Families, Housing, Community Services and Indigenous Affairs, August 2011
Authored by Rashmi Kumar, NC OSS Senior Policy Officer
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Carers provide informal care to people who need assistance due to disability, mental illness, chronic conditions, terminal illness or due to being frail aged. In this report, Access Economics examines the amount of informal care being provided in Australia today. Placing a dollar value on the work of informal carers is the first step in evaluating whether the current use of informal and formal care models is socially optimal, in terms of both efficiency and equity.

Section 1 identifies who are Australia’s carers, providing a profile of carers and the care needs of the people they care for.

In 2010, over 1 in 8 Australians (2.87 million people) are estimated to be providing informal care. This represents 13.1% of Australia’s population, a higher share than in 2003. ≫ 540,000 (1 in 40 Australians) are ‘primary carers’, providing the majority of the recipient’s care ≫ In absolute terms, there are around 310,000 more carers in 2010 compared to 2003, and 65,400 more primary carers. The number of carers, and primary carers, is increasing at some 2% per annum (around the same rate as population growth).

Informal carers together provide an estimated 1.32 billion hours of care in 2010. ≫ This is equivalent to each carer providing an average of 460 hours of care per year or 9 hours per week ≫ However, care hours are in fact much more unevenly distributed, with primary carers providing 54% or 714 million hours annually, despite representing only 19% of all carers.

Section 2 looks at two measures of how this time spent by carers could be valued.

≫ In 2010, an estimated 129,900 carers will not be employed due to their caring responsibilities (1.1% of Australia’s workforce). The opportunity cost of time devoted to informal care, measured as reduction in paid employment due to caring, provides a ‘lower bound’ estimate of $6.5 billion (equivalent to 0.5% of GDP and 9.5% of the value of formal health care). This measure reveals the resources that are diverted each year from production in the formal economy to informal care – Rates of employment and labour force participation among carers are substantially lower than the Australian average, even when standardised from differing age-gender profiles.

≫ The replacement valuation reveals the resources that would need to be diverted each year from the formal economy to replace the work done by informal carers, were their services no longer available. If all hours of informal care were replaced with services purchased from formal care providers and provided in the home, the replacement value would be $40.9 billion (equivalent to 3.2% of GDP and 60% of other formal health care).

Also likely to be substantial, but not costed here, are the impacts of caring on the health and wellbeing of carers. Often the burden of pain and suffering associated with depression, musculoskeletal injuries and other problems dwarfs the financial costs. ≫ On a relative prevalence basis, the sleep impacts of caring alone may exceed $1 billion per annum,
The relativities and public subsidy components are shown in Chart I.

Section 5 outlines the questions and challenges that face policymakers. It describes how the analysis in this report can inform these questions, as well as further work that is needed.

The relay to formal care workers. There is relatively little funded training for informal carers

A case study based on a randomised clinical trial of an informal carer training program in the UK showed that, if the same program was delivered in Australia, benefits would exceed costs by over $19,000 per annum per person – through reducing reliance on formal health sector and community services relative to a situation of no carer training.

A similar randomised controlled trial should be conducted in Australia to confirm these modelled findings, potentially across a variety of care settings.

The analysis conducted in this report based on average costs of care shows that combinations of informal care and community-based formal care services provided together are generally lower cost than institutionalised care, using an opportunity cost valuation of carer’s time, excluding health costs to the carer and noting that the cost of residential care includes a housing component. For 2010 the estimated relativities per person on this basis are:

Informal primary care with HACC services is lowest at $12,983; informal primary care with CACP costs around $23,425; EACH plus informal primary care is around $51,264; EACH-D plus informal primary care is around $53,831; RAC low care is around $44,319; while RAC high care is greatest at $69,178 per person in 2010

The demand and supply of informal care will be influenced by many factors in the future, most notably:

Many chronic and disabling conditions are highly age-related suggesting that, with population ageing, more people may require care in the future (a greater demand for care), and

There will be relatively fewer younger people, greater mobility and dispersion of families, increased female labour force participation, higher rates of relationship breakdown and single-person households, and potentially reduced propensity to care from Generation X and Y relative to previous generations, all of which

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Young carers, an often overlooked group, are at high risk of long-term disadvantage as result of missed education opportunities and compromised high school performance. The ‘25-hour rule’ which limits recipients of Carer Payment to a maximum of 25 hours per week of study, work and travel, compounds the many difficulties faced by young carers in obtaining certain tertiary qualifications.

A case study interview with Chantelle, 21, who has cared for her mother since she was 12, shows that by being unable to undertake a medical degree, for which she gained entry, due to the ‘25-hour rule’ Chantelle will earn less than 60% of what she could have as a doctor i.e. $3.1 million as a psychologist rather than $5.45 million over a lifetime, in real 2010 dollars. The difference is $2.35 million, comprising lost tax revenue of $0.5 million and a loss to Chantelle of $1.9 million.

Section 4 examines the level of public (Government) support for carers relative to other models of care.

Governments are increasingly recognising the contribution of family carers, and the costs they bear in providing informal care. The level of Government support, both through welfare support payments and service provision, has increased over the past few years.

However, in contrast to the education and training provided to formal care workers, there is relatively little funded training for informal carers

One case study model presented in this report was of a hypothecated carer, ‘Karen’, with mild-moderate depression, stress-related angina (a cardiovascular condition), and chronic lower back pain. The total financial impact of all three conditions is over $33,000 in 2010. Adding in the cost of the loss of Karen’s healthy life (about 27% of a healthy life year is lost to the conditions), the total impact is nearly $79,000. Karen bears 56% of the financial costs (mainly lost income but also health costs over $1,000), while the Government bears 21%. Karen bears all the wellbeing loss.

Informal primary care with HACC services is lowest at $12,983; informal primary care with CACP costs around $23,425; EACH plus informal primary care is around $51,264; EACH-D plus informal primary care is around $53,831; RAC low care is around $44,319; while RAC high care is greatest at $69,178 per person in 2010

The relativities and public subsidy components are shown in Chart I.

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There will be relatively fewer younger people, greater mobility and dispersion of families, increased female labour force participation, higher rates of relationship breakdown and single-person households, and potentially reduced propensity to care from Generation X and Y relative to previous generations, all of which
may reduce the desire or ability to provide informal care (a lower supply of informal care, or growth of supply lower than demand growth).

As Chart II shows, the ‘carer ratio’, of primary carers to older people with a disability, is projected to fall from 60% now to under 40% by mid-century reflecting that demand for informal care will substantially outstrip supply.

The growing gap between demand and supply was not substantially affected by three scenario analyses.

- An overall decline in the propensity of people to care, represented by a 20% across-the-board decrease in carer rates, increased the base case deficit by 12.1% in 2050
- 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, increased the base case deficit by 5.5% in 2050
- An increase in the availability of carers due to converging male and female life expectancy, represented by a 20% increase in carer rates in the 65+ age group, reduced the base case deficit by 3.1% in 2050.

The future mix of care – between community and RAC, and between formal and informal services – is unclear – reflecting the changing pattern of disease (favouring RAC and formal care services), shifting social preferences (generally towards community care) and supply constraints (notably potentially fewer informal carers). The third InterGenerational Report (Treasury, 2010) concluded there will be a much larger relative increase in spending on RAC than on community care, with formal care expenditure increasing from 0.8% of GDP today to 1.8% of GDP in 2049-50.

Given that investments in informal carer support have been shown to be cost-effective, there is a strong case to prioritise support for carers that can delay or prevent costly institutionalisation, including:

- Respite care
- Income support
- Education and training, and
- Preventive health care (e.g. lifting techniques, health checks and a personalised health record to help maintain carers’ health).

Such support for carers will help ensure and enhance future labour productivity across the formal and informal sectors of the economy, as well as meeting Australia’s obligations to optimise wellbeing for the frail aged those disadvantaged by disability, mental illness or chronic illness.

ENDNOTES

1. ‘Informal care’ refers to care provided by unpaid family carers.

Caregiving doesn’t crowd out working

The labour market impacts of caregiving are much smaller than previously thought, according to new research from ANU economics professor Andrew Leigh

The study, conducted by ANU economics Professor Andrew Leigh, focused on individuals who voluntarily provide care for an elderly or disabled person. It determined the impact of caregiving on paid employment, wages, and life satisfaction.

What distinguishes this study from prior research on caregiving is that it follows the same individuals over a seven-year period, and looks to see what happened to their labour market outcomes when they changed from being a carer to a non-carer (or vice versa).

"Much of the previous research has simply compared carers and non-carers,” said Professor Leigh. "When you do that, you find very large gaps between the labour market outcomes of the two groups.

"But we should not mistake correlation with causation. When you look at the same individuals over time, the causal impact of caregiving on wages and life satisfaction seems to be close to zero.”

He added that while the causal impact of caregiving on employment is negative, it is much smaller than previous studies have suggested.

"For example, while caregivers have a labour participation rate that is 20-28 percentage points lower than non-carers, this impact drops to 4-6 percentage points when looking at within-person changes,” said Professor Leigh.

“These results do not detract from the vast contribution that unpaid carers make to the wellbeing of elderly and disabled people. Australians should recognise that millions of hours of care are provided annually by friends and family.

“But it would be a mistake to assume that these hours are all coming at the expense of paid employment.

“Policymakers should also be modest about the ability of government policies to increase the labour market attachment of caregivers.”

The research – ‘Informal Care and Labor Market Participation’ – is forthcoming in the journal Labour Economics.


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Disability, ageing and carers in Australia

A SUMMARY OF FINDINGS FROM THE AUSTRALIAN BUREAU OF STATISTICS

OVERVIEW

Disability

Four million people in Australia (18.5%) reported having a disability in 2009, according to the results of the Survey of Disability, Ageing and Carers (SDAC). For the purposes of SDAC, disability is defined as any limitation, restriction or impairment which restricts everyday activities and has lasted or is likely to last for at least six months.

Examples range from loss of sight that is not corrected by glasses, to arthritis which causes difficulty dressing, to advanced dementia that requires constant help and supervision. Males and females were similarly affected by disability (18% and 19% respectively).

The rate of disability increased with age. Almost nine in ten people aged 90 and over (88%) had a disability, compared with 3.4% of those aged four years and under.

The prevalence of disability in Australia has fallen 1.5 percentage points since 2003. In 2003, 20% of Australians had a reported disability, compared with 18.5% in 2009. After removing the effects of different age structures the age standardised rate also fell by 2.1 percentage points.

The rate of profound or severe limitation in the core activities of communication, mobility and self-care declined, from 6.3% in 2003 to 5.8% in 2009. Much of the decrease in the prevalence of disability between 2003 and 2009 is due to a decline in the proportion of Australians disabled by physical health conditions, such as asthma and heart disease.

In 2009, there were 2.6 million carers who provided assistance to those who needed help because of disability or old age.

CARERS

In 2009, there were 2.6 million carers who provided assistance to those who needed help because of disability or old age. Just under one third of these (29%) were primary carers; that is, people who provided the majority of the...
informal help needed by a person with a disability or aged 60 years and over. Over two-thirds of primary carers (68%) were women.

**DISABILITY**

Just under one in five Australians (18.5%) had a reported disability in 2009. A further 21% had a long-term health condition that did not restrict their everyday activities. The remaining 60% of the Australian population had neither a disability nor a long-term health condition. Of those with a reported disability, 87% had a specific limitation or restriction; that is, an impairment restricting their ability to perform communication, mobility or self-care activities, or a restriction associated with schooling or employment.

**DISABILITY PREVALENCE**

The disability rate increases steadily with age, with younger people less likely to report a disability than older people. Of those aged four years and under, 3.4% were affected by disability, compared with 40% of those aged between 65 and 69 and 88% of those aged 90 years and over.

Rates of disability and rates of profound or severe core-activity limitation for 5 to 14 year old males (11% and 6.6% respectively) were close to double those for females in the same age group (6.1% and 3.0% respectively). In contrast, women aged 90 years and over had a higher rate of profound or severe core-activity limitations (75%) than men of the same age (58%).

While the prevalence of disability amongst the Australian population declined 1.5 percentage points, the decrease is particularly noticeable in the younger age groups. From 2003 to 2009, the disability rate for 15 to 24 year olds fell from 9.0% to 6.6%. Over the same period the rate of disability also decreased for those aged between 25 and 34 from 11% to 8.6%. Similarly, 22% of 45 to 54 year olds reported a disability in 2003, compared with 18% in 2009.

**CONDITIONS**

The incidence of disability caused by physical conditions, as opposed to mental or behavioural disorders, dropped from 17% in 2003, to 15% in 2009. For instance, in 2003, 6.8% of Australians had a disability primarily caused by musculoskeletal disorders such as arthritis and back problems, with this proportion declining to 6.5% in 2009. Likewise, the incidence of disability caused by diseases of the circulatory system dropped from 1.8% to 1.4%. In 2003, 8.8% of people aged in the 65 years and older group reported a disability due to diseases of the circulatory system, compared with 7.4% in 2009.

The incidence of disability caused by asthma also declined, from 0.8% in 2003 to 0.5% in 2009. Amongst younger people (0 to 17 years), the incidence of disability caused by asthma almost halved between 2003 and 2009, from 0.9% in 2003 to 0.5% in 2009. Of those aged between 18 and 44 years, the incidence of asthma-related disability also decreased, from 0.5% in 2003 to 0.3%. In addition, for this age group, the proportion of people with a disability due to back problems reduced, from 2.6% in 2003 to 1.9% in 2009.

The incidence of disability due to back problems also declined amongst those aged between 45 and 64 years. In this age group, 5.2% of people reported a disability as a result of back problems in 2009, compared with 6.0% in 2003. By contrast, the prevalence of disability resultant from back problems amongst those aged 65 and over has increased since 2003, from 4.9% to 6.3%.

**CARERS**

The proportion of Australians involved in caring for a person with a disability or an older person declined from 13% in 2003 to 12% in 2009, in line with the decrease in disability prevalence. In 2009, just under one in three carers (29%) were identified as a primary carer; that is, a person who provided the majority of help to a person with a disability or aged 60 years and over. In this age group, 5.2% of people reported a disability as a result of back problems in 2009, compared with 6.0% in 2003. By contrast, the prevalence of disability resultant from back problems amongst those aged 45 and 64 years and over has increased since 2003, from 4.9% to 6.3%.
PROVIDERS OF DISABILITY ASSISTANCE

Where a person has a disability that requires need for assistance, there are often a range of sources from which this help is accessed, according to the Australian Bureau of Statistics.

Informal providers of assistance

Informal providers of assistance were typically close family members. In the case of adults with disabilities, this was most likely to be partners (41%) or children (28%) while parents (18%) were more likely to be providing help with children, regardless of their age (many elderly parents provide assistance to adult children).

Reliance on informal assistance from family and friends was particularly noticeable for the three core activities (Graph 2):

➤ Of all those receiving informal assistance with self-care, 51% received this help from partners and 23% from parents
➤ Of all those receiving assistance with mobility, 44% received help from partners, 27% from children and 18% from parents, and
➤ Of all those receiving assistance with communication, 64% received help from their parents.

Providers of informal assistance were typically close family members.

Formal providers of assistance

Formal providers of assistance comprised a mix of government, private non-profit organisations and private commercial organisations. The government provided most formal assistance for both core activities (Graph 4) and non-core activities (Graph 5). It is likely that many private
commercial agencies also received funding from the government.

While the government provided the bulk of assistance with most activities, private commercial agencies provided more assistance with cognitive emotional tasks (56%), health care (55%) and property maintenance (58%). Private non-profit agencies also provided more assistance than private commercial organisations with self-care tasks (5%), mobility (5%), transport (7%) and meal preparation (9%).

### Unmet need for assistance

Looking specifically at unmet need for assistance with core activities (self-care, mobility and communication) an interesting change occurred between males and females. In childhood (0-14 years), males were more likely to be reported as needing more assistance with these activities than females (28% and 21% respectively) (Graph 6).

For older people however, the situation reversed. From the age of about 35 years onwards, females were more likely to report needing more assistance with these activities than males. The gap between the sexes widened with increasing age.
It is estimated that in 2003 there were 474,600 primary carers providing care to a person because of disability or old age. In coming decades, as the Australian population ages, the number of carers is projected to increase. Despite the large number of carers in Australia and the likely increase in their numbers, relatively little is known about the impact upon families of providing care. This report begins to fill the gap.

The analysis is based upon data from a nationally representative survey, conducted in 2006, of 1,002 carers who receive an Australian Government payment directed towards carers (Carer Payment and/or Carer Allowance). Carers were selected from a random sample of 5,000 carers from Centrelink records who, at June 2006, were receiving Carer Payment and/or Carer Allowance.¹

This research was a collaborative project between the Australian Institute of Family Studies (AIFS) and the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

The aims of this report are to:
> Examine the effect of caring on family and social relationships
> Document the social, emotional, physical and financial impact on families of caring for a person with a disability
> Examine the effect of caring on labour force status.

**KEY FINDINGS**  
**Mental health**

One of the key issues to emerge from this research is that carers and their families experience high rates of mental health problems. Carers had significantly worse mental health and vitality and higher rates of depression than the general population. Differences between carers and the general population on these variables were evident for carers of all age groups, except when carers were 65 years or older.

When we used the mental health scale as an indicator of clinical levels of depression, the rates of clinical levels of depression in the previous 4-week period were 19% of female carers and 13% of male carers, while for females and males in the general population they were 11% and 8% respectively. Fifty-one per cent of female carers and 30.7% of males also reported that they had been depressed for 6 months or more since they started caring (we henceforth refer to this period of depression as a ‘depressive episode’).

Family members also experienced high levels of depression, with 27.3% of partners, 12.1% of parents and 10.6% of offspring of carers experiencing a depressive episode of 6 months or more since caring began. Moreover, the carer’s experience of depression was associated with other family members’ experiences. Regardless of whether they had a disability, partners and children of carers were two to five times more likely to experience a depressive episode when the carer had also experienced a depressive episode of 6 months or more since they started caring. Higher rates of depressive episodes for partners with no disabling condition and children with and without a disability were also evident when there were problems in family functioning.

The risk of carers and family members experiencing a depressive episode of 6 months or more was greatest in the first year of caring. The risk of carers experiencing a first depressive episode of at least 6 months’ duration was greatest in the first year of caring (over 13% of carers), but over the next 20 years was fairly stable at about 3%. For other family members, the first year of caring accounted for 41.6% of all the first depressive episodes experienced by people with a disability and 17.9% of first depressive episodes of other household members.

Several factors were associated with carers having more mental health problems, worse vitality and higher rates of depression than people from the general population. These included: caring for a child with a disability; caring for a person with a disability with high care needs; caring for more than one person with a disability; having another care role (that is, also looking after children who did not have a disabling condition); experiencing one or more problems in dimensions of family functioning; and needing more support than they were currently receiving.
Physical health

Almost twice as many carers were in poorer physical health than the general population. These elevated rates of poor physical health were not the result of carers being older than the general population, as female carers had poorer physical health than females in the general population for all age categories, except when aged 65 years or more.²

Several factors were associated with higher self-ratings of poor physical health of carers. These included: caring for a person with a disability who has high care needs, caring for more than one person with a disability, and having one or more problems in dimensions of family functioning. Carers who indicated that they needed more support also had higher rates of poor physical health than carers who said the support they received was ‘about right’. As many of the risk factors for poor physical health of carers were the same as those for poor mental health, a coordinated bio-psychosocial intervention may best meet the needs of carers and their families.

Employment

The employment chapter of this report provides direct evidence on the changes in labour force status since starting caring. It is clear that many carers had stopped working since commencing caring and, when asked why, a large majority said that it was because of their caring responsibilities. Interestingly, at least among non-employed carers, there was little difference in the employment rates prior to commencing caring between those who received only Carer Allowance and those who received Carer Payment. The fact that a large number of non-employed carers of working age expressed a desire to be in paid employment suggests that policies that support carers who want to be in paid employment may be worthwhile.

Financial hardship

Compared to families from the general population, a higher proportion of families of carers suffered from greater financial hardship. Irrespective of which payment the carers’ families received, families who cared for a person with a disability experienced a higher level of financial hardship than the general population. For example, 30% of families with a carer receiving Carer Allowance and 29.2% of families with a carer receiving Carer Payment had experienced difficulty in paying electricity, gas or telephone bills on time. Only 14.6% of the general population indicated that they experienced financial hardship in this area.

Relationships and support networks

Carers’ support networks, carers’ relationships, relationship breakdown and family functioning were a major focus of the study. Although most carers had supportive people around them, there was a substantial minority of carers (one in five) who had no assistance from other people in caring for the person or people with a disability. For the majority of carers who did have support, the support provided was not without some issues attached. Even when carers had people to support them and the person with a disability, one in five carers had disagreements with others about caring. Of those carers who had support people, one in five had support people who had some problems with cooperating with other supporters about the care for the person with a disability. These findings highlight that coordination, disagreement and conflict can ensue from caring for a person with a disability and these can be barriers to the effective provision of informal care.

Compared to families from the general population, a higher proportion of families of carers suffered from greater financial hardship.

Carers were satisfied with their relationships with their partners, or at least they were as satisfied as non-carers from the general population – even when their partner was the person with a disability. Although provision of care for a person with a disability was not associated with dissatisfaction with carers’ relationships (that is, the relationship between carers and their partners, their children and their parents, and the relationship between carers’ partners and children), it did seem to affect carers’ satisfaction with how their children got along with one another. This is consistent with research showing the negative impact of caring for a person with a disability on non-disabled siblings, perhaps because of the reduction in attention they receive (see Higgins, Bailey, & Pearce, 2005).

Conflict is the aspect of family functioning that carers most frequently see as problematic (one in three identified this aspect as a problem). Carers of someone with a psychiatric disability are the most likely to report two or more problems in family functioning, with carers of someone with a physical disability the least likely. Poor family functioning is associated with greater care needs of the person with a disability, suggesting that the level of
impairment is a good proxy measure of the likely impact of caring for someone with a disability on broader family relationships.

The report also provides new data on the timing and risk of increased arguments and relationship breakdown between carers and their partners since caring began. When a partner is being cared for and there is a relationship separation, the carer will usually cease being a carer, and therefore no longer be eligible for Carer Payment and/or Carer Allowance. Consequently, we restricted the sample to carers of a person with a disability who was not a partner. The results showed a heightened risk of arguments between carers and their partners shortly after commencement of caring, but an even distribution of the risk of relationship separation over time (after accounting for the number of carers still caring in each subsequent year). Almost one in three female carers aged 50 or less had separated or divorced since they started caring, while one in seven over the age of 50 had separated or divorced since they started caring. These data suggest that support services that focus on addressing relationship conflict in the first year of caring and target carers under the age of 50 may reduce separations and arguments between spouses.

**Hours of care**

Sixty per cent of carers reported that they cared for the person with a disability for more than 100 hours per week. The 100 or more hours of care per week was likely to include the time associated with direct care as well as the time associated with monitoring the person with a disability (being ‘on call’).

While the number of hours of caring may not always represent direct care, even being on call has implications for the lives of the carer and their families. Carers may not feel that they can leave the person in their care by themselves, which has implications for engaging in a social life outside of the house, independent of the carer, and also in employment.

**Multiple care responsibilities**

Thirteen per cent of primary carers cared for two or three people with a disability. In addition, almost one in three cared for at least one child along with the person with a disability (who could also be a child). Caring for more than one person with a disability and/or caring for a person or child with a disability while caring for other children were associated with carers having significantly worse mental health and vitality and higher rates of depression. Moreover, carers aged 18 to 50 – the age when they would most likely be caring for children – had the worst mental health and vitality and the highest rates of depression. These data suggest that carers raising children (both with and without a disability) or those caring for multiple family members with a disability are under significant stress.

**Support services**

The use of support services by families was also explored. Although the focus of the survey was not on the support needs of carers, we asked one general question on the types of services carers and their families used. Almost half of carers’ families did not use any support services, with the most commonly used services being respite care (13%) or a general practitioner (11%). The general nature of the question may have led to some underestimation of the number of services used by families. However, underestimation of service use was unlikely to be large, as several services, including respite, were specifically mentioned by interviewers. Few families reported using respite care – three out of five used respite for less than 20 hours per month, although close to one in five used it for more than 50 hours per month.

**SUMMARY**

This report has documented the significant emotional costs for all family members – the primary carer, the person with a disability and other family members – associated with caring. Carers raising children (both children who have a disability and those who do not) or caring for multiple family members with a disability were at particular risk of worse mental health outcomes. The evidence in this report also suggests that aspects of the family environment (such as good family functioning and adequate support to the carer) are critical to the good mental health of family members and the physical health of carers. However, there are relationship costs for some groups; for example, one in three carers under the age of 50 had separated from their partner since they started caring. The economic costs to the carer and their families were also considerable. Many carers gave up work to care for the person with a disability, and three-quarters of those who were not employed expressed a desire to work. Also, compared to families from the general population, a greater proportion of carers’ families suffered from greater financial hardship.

This report documents the substantial social, emotional and economic costs of caring for a person with a disability, not only for the primary carer but also for the family. The challenge for policy makers and the Australian community is to develop policies and an environment that minimise these costs so that families can care for their relatives with a disability.

**FOOTNOTES**

1. Sample records contained information on contact details and payment type only.
2. There were insufficient numbers of male carers in the different age categories to conduct the same comparisons for male carers.
3. Interviewers asked the following question: “Could you please tell me whether you or [the person with a disability] (or anyone else in your household) use any disability services like respite, counselling, disability employment services or carer support services.”
4. When a partner is being cared for and there is a relationship separation, the carer will usually cease being a carer, and therefore no longer be eligible for Carer Payment and/or Carer Allowance. Consequently, we restricted the sample to carers of a person with a disability who was not a partner.

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30 Carers: Ageing and Disability

Issues in Society | Volume 342
EXECUTIVE SUMMARY

The current disability support system is underfunded, unfair, fragmented, and inefficient. It gives people with a disability little choice, no certainty of access to appropriate supports and little scope to participate in the community. People with disabilities, their carers, service providers, workers in the industry and governments all want change.

Most people know little about Australia’s current disability system and do not know how poorly they would be served were they to need it – this is a system marked by invisible deprivation and lost opportunities. Yet major disability can happen to anyone and at anytime – a simple fall can lead to quadriplegia, and an illness to severe brain damage. Most families and individuals cannot adequately prepare for the large costs of lifetime care and support. The costs of lifetime care and support can be so high that the risks and costs need to be pooled.

It was against that background that the Australian Government asked the Productivity Commission to look at the costs, cost effectiveness, benefits and feasibility of replacing the current arrangements with a properly funded and managed long-term disability scheme. This short summary outlines the Commission’s ideas for a new way of meeting the care and support needs of people with a disability.

Most people know little about Australia’s current disability system and don’t know how poorly they would be served if they were to need it.

The following table provides a snapshot of the current system and what the Commission thinks it should look like. There is also a more detailed overview, which includes the 86 recommendations of the report. The Commission has produced an additional 1,200 pages of supporting material setting out how a new scheme could be implemented at a detailed level and providing in-depth evidence for the recommended approaches. The inquiry drew from 23 days of testimony in formal hearings held around Australia and extensive evidence from nearly 1,100 submissions from people with disabilities, carers, service providers, governments and business.


The last page of the executive summary indicates what has changed since the draft report.

The bottom line of this report is that a new national scheme for disability – like Medicare – is feasible, that it would produce very large benefits for Australians and that a realistic and clear implementation pathway is available.

The Commission also recommends the establishment of a National Injury Insurance Scheme – run at the state and territory level – that would provide lifetime support for people acquiring a catastrophic injury from an accident. It would draw on existing arrangements in some states.
1.1 OVERCOMING THE PROBLEMS OF THE PRESENT SYSTEM

<table>
<thead>
<tr>
<th>Current problem</th>
<th>How the proposed arrangements would address the current problems</th>
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<tbody>
<tr>
<td>Poor national insurance (people without a disability have no clear coverage if they acquire a disability)</td>
<td>Full coverage of all Australians for the costs of long-term disability care and support, so people without a disability could feel confident that they or their families would be supported in the event of a significant disability. Insurance has value for people even if they make no claims.</td>
</tr>
<tr>
<td>Inequitable (e.g. what you receive in assistance depends on where you live)</td>
<td>A national scheme with national standards and entitlements that would cover people with significant disabilities arising from non-accidents. State-based arrangements for no-fault insurance coverage of all catastrophic accidents – with minimum national standards.</td>
</tr>
<tr>
<td>Underfunded with long waiting lists</td>
<td>Funding would be doubled and tied to the Australian Government’s revenue-raising capacity (characterised by more efficient and sustainable taxes).</td>
</tr>
<tr>
<td>Failures to intervene early (e.g. people stuck in hospital because of insufficient funds for minor home modifications)</td>
<td>The schemes, like all insurers, would aim to minimise long-term costs, so they would have a strong incentive to undertake early intervention where it is cost effective. The scheme would spend dollars to save more dollars and people would not have to wait for basic supports like wheelchairs and personal care.</td>
</tr>
<tr>
<td>Fragmented</td>
<td>Universal schemes; locally responsive within nationally coherent framework; funds and assessments portable across borders and support providers.</td>
</tr>
<tr>
<td>Lack of clear responsibilities</td>
<td>Assessments under the NDIS would identify and facilitate referrals to the right supports outside the NDIS.</td>
</tr>
<tr>
<td>People with disabilities and their families are disempowered and have little choice</td>
<td>People would be able to choose their provider or providers. They could choose to have a disability support organisation manage their packages or to act in other ways on their behalf. They would be able to manage their own funds if they wish (within rules).</td>
</tr>
<tr>
<td>Little future planning</td>
<td>The NDIS would encourage and support people into work and/or being more involved in the community. People’s short and long-term plans would be reflected in their individual support packages.</td>
</tr>
<tr>
<td>Family and carers are devalued</td>
<td>The support provided by families would be considered in assessments, and where appropriate, carers also assessed and given additional supports.</td>
</tr>
<tr>
<td>Insufficient engagement with the community</td>
<td>The NDIS would leverage a bigger role for community groups and not-for-profit organisations to connect people with disabilities with the community.</td>
</tr>
<tr>
<td>Economically unsustainable</td>
<td>Appropriate funding would stabilise the withdrawal of informal care under the present crisis-based system (which is leading to the costly withdrawal of informal supports by non-coping carers).</td>
</tr>
<tr>
<td>Inefficient with weak governance</td>
<td>The new scheme would be run to insurance principles by a commercial board with strong and constant monitoring by Treasury. Advice from a council of stakeholders (people with disabilities, carers and providers). People with disabilities and their families would have more control over the services they receive. They would have a strong incentive to maximise outcomes, and a direct stake in cutting waste and unnecessary services. Many safeguards to ensure costs did not get out of control. Benchmarking against schemes overseas and between the NIIS and NDIS.</td>
</tr>
<tr>
<td>People have no confidence about the future: what services will and will not be available</td>
<td>The scheme would focus on long-term care and support needs. People would have clear entitlements to their assessed needs. There would be arrangements to guide people through the system, with strong complaints and appeals mechanisms. Strong reserves to buffer the insurance fund. The scheme funds would not be tied to the annual budget cycle, but would have mandated funding hypothecated to a separate fund.</td>
</tr>
<tr>
<td>Poor information, poor data collection for disability services to ensure efficient management</td>
<td>Information provision through web and other means by a single national agency, disability support organisations to act on behalf of people, availability of objective information about supplier performance; coherent collection of data by the scheme to manage costs and to assess outcomes.</td>
</tr>
<tr>
<td>Poor evidence base</td>
<td>Research function and evidence-based practice.</td>
</tr>
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</table>
### 1.2 KEY FEATURES OF THE NDIS AND NIIS

The largest scheme would be the National Disability Insurance Scheme. It would be like Medicare, in that all Australians with a significant and ongoing disability would get long-term care and support (but not income, which would be left to private insurance and to the Australian Government’s income support system). A second smaller scheme (the National Injury Insurance Scheme) would cover the lifetime care and support needs of people who acquire a catastrophic injury from an accident. The smaller scheme would be based on the motor accident compensation schemes that operate in some states and territories.

<table>
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<tr>
<th>What kind of scheme is proposed?</th>
<th>NATIONAL DISABILITY INSURANCE SCHEME (NDIS)</th>
<th>NATIONAL INJURY INSURANCE SCHEME (NIIS)</th>
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<tbody>
<tr>
<td>A national scheme to provide insurance cover for all Australians in the event of significant disability. Its main function would be to fund long-term high quality care and support. Other important roles include providing referrals, quality assurance and diffusion of best practice.</td>
<td>A federated model of separate, state-based no-fault schemes providing lifetime care and support to all people newly affected by catastrophic injury. It would comprise a system of premium-funded, nationally consistent minimum care and support arrangements for people suffering catastrophic injuries.</td>
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| Who would be covered? | All Australians would be insured. Funded support packages would be targeted at all people with significant and permanent disability, whose assistance needs could not be met without taxpayer funding. Anyone with, or affected by, a disability could approach the scheme for information and referrals. | All causes of catastrophic injuries, including those related to motor vehicle accidents, medical accidents, criminal injury and general accidents occurring within the community or at home. Coverage would be irrespective of how the injury was acquired, and would only cover new catastrophic cases. |

| What it would provide? | The NDIS would provide reasonable and necessary supports across the full range of long-term disability supports currently provided by specialist providers. Services such as health, public housing, public transport and mainstream education and employment services, would remain outside the NDIS, with the NDIS providing referrals to them. | The NIIS would provide lifetime care and support services broadly equivalent to those provided under the Victorian TAC and NSW Lifetime Care and Support scheme. This includes reasonable and necessary attendant care services; medical/hospital treatment and rehabilitation services; home and vehicle modifications; aids and appliances; educational support, and vocational and social rehabilitation; and domestic assistance. |

| What would be the cost? | The scheme would cost approximately $6.5 billion above current spending (around $295 per Australian). Total expenditure would be around $13.5 billion per annum. | Net annual costs of a comprehensive no-fault scheme covering all catastrophic injuries could be around $830 million (around $35 per Australian). |

| How it would be funded? | The Australian Government should direct payments from consolidated revenue into a ‘National Disability Insurance Premium Fund’, using an agreed formula entrenched in legislation. | The additional funding required for the NIIS would come from existing insurance premium income sources. |

| How many people would receive funding? | Around 410,000 people would receive direct scheme funding. It would cover existing and new cases. | The NIIS would cover new incidence of catastrophic injury (around 900-1,000 people each year), but over the long run, 30,000 people would be in the scheme. |

| When would the scheme commence? | A full-scale rollout in a few regions of Australia in mid-2014. It would extend to all Australia in 2015-16 covering those most in need, and then progressively expand to all significant disabilities by 2018-19. | As a starting point, jurisdictions should implement no-fault catastrophic injury schemes for motor vehicle accidents by the end of 2013. The NIIS would cover all catastrophic injury by the end of 2015. |
People with disabilities and their families are celebrating the Productivity Commission’s recommendation of a new $6.5 billion insurance scheme to cover everyone who suffers a disability. Barbara Miller and Stephen Dziedzic report

They say the move comes after many years of hard campaigning for a Federal Government-funded national insurance scheme for life-long care and support. Some have concerns about the length of time it will take to implement the scheme, but they believe the move will lead to a cultural change in the way people with disabilities are perceived. Heike Fabig, the president of the Association for Children with Disability in NSW, has two children with cerebral palsy.

“I can tell you we had a committee meeting this morning when this announcement was made, and we were sitting ready with a cake, and by the time we came to cutting the cake there were a few tears in the room because we’ve been fighting for this for a very long time,” she said.

She says it is a “fantastic and very important” new beginning for people with a disability in Australia.

“The big hope that we have is that finally our children and anyone with a disability – whether they’re adult or child – are recognised as a person first and foremost,” she said.

“A person who may need a few extra helps here or there – who may need a wheelchair, who may need speech therapy – but first and foremost people rather than charity recipients who have to beg for every piece of equipment and every bit of therapy that we think they have a right to.”

Lesley Baker, who looks after her 33-year-old son who was born with severe disabilities, says she has high hopes for the scheme.

“I’m just delighted. It is an enormous relief to all of us who have anything to do with disability,” she said.

“I think it will make specialties that Ben might need – physiotherapy, things like that – able to be achieved now whereas they were something that were sort of pipe dreams before. I will be able to make greater decisions and be able to go ahead with things that I would like to do for him and with him.

“I see it as enormous because to me it’s something that until it hits you, until you’re actually facing it, you have no idea what it entails. So this way everybody will have the reassurance of assistance.”

Bittersweet victory

It is not clear exactly how many years it will be before the scheme is fully operational across the country, but Prime Minister Julia Gillard said the Government was ready to “make a start”. That is a worry for Kelly Vincent, who is an Upper House MP in South Australia for the Dignity Party. She has cerebral palsy.

“I think that people with disabilities are often asked to compromise way too much, are often asked to settle for a lower standard or for second best, rather than having full control over our lives and services that we can access,” she said.

“So I think that the more we can move towards [carer teams] which help to achieve autonomy to give control and dignity to people with disabilities, the better.”

Ms Vincent says the announcement represents a bittersweet victory.

“It’s a relief, but it’s relief that comes after a lot of hard work and after people with disabilities living their lives to an inadequate standard for many many years. So this is a possible light at the end of a very long tunnel.”

And carers like Ms Fabig agree that change could still be a long time coming.

“We know that tomorrow it’s back to the daily grind and we’re a long way off getting the services that for example I need for my children,” she said.

Potential roadblock

The Government has not yet said how it will pay for the scheme, saying it needs to have detailed discussions with the states. And it is already facing a potential roadblock, with the West Australian Premier Colin Barnett signalling he will not sign up to a federal takeover of disability funding.

The Productivity Commission says it could take up to seven years to phase in the scheme, so the Government has promised to spend $10 million immediately on technical policy advice. It will also set up a group to provide expert advice on setting up the scheme and another to consult with the states about how it will be implemented. But getting the states on board may not be easy after Mr Barnett warned he would not tear up the existing disability funding systems in his state.

“The West Australian Government in its last budget allocated over $600 million to not-for-profit community-based groups, and I’m not in any way inclined to simply put my hand up and say yes to another clumsy Commonwealth attempt at takeover,” he said.

“This is all about political power for autocrats in Canberra.”

There is a separate debate about whether the scheme should be funded out of government revenue or by imposing a levy on taxpayers. The Coalition has been attacking the Government for introducing new taxes, like the mining tax and the carbon tax. But Opposition disabilities spokesman Mitch Fifield says the Coalition is keeping an open mind to all proposals.

“People with a disability and their families aren’t terribly fussed about where the money comes from, they just want the system fixed,” he said.

But Greens Senator Rachel Siewert says the Government should have made a firmer funding commitment than the $10 million for policy advice.

“What we want to know is are they committed to that funding? If so, when will they be making that announcement? How will it be rolled out?” she said.
Most families and individuals cannot adequately prepare for the risk and financial impact of significant disability. The costs of lifetime care can be so substantial that the risks and costs need to be pooled.

The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports. The stresses on the system are growing, with rising costs for all governments.

There should be a new national scheme – the National Disability Insurance Scheme (NDIS) – that provides insurance cover for all Australians in the event of significant disability. Funding of the scheme should be a core function of government (just like Medicare).

The main function (and source of cost) of the NDIS would be to fund long-term high quality care and support (but not income replacement) for people with significant disabilities. Everyone would be insured and around 410,000 people would receive scheme funding support.

The NDIS would have other roles. It would aim to better link the community and people with disabilities, including by using not-for-profit organisations. It would also provide information to people, help break down stereotypes, and ensure quality assurance and diffusion of best practice among providers.

The benefits of the scheme would significantly outweigh the costs. People would know that, if they or a member of their family acquired a significant disability, there would be a properly financed, comprehensive, cohesive system to support them. The NDIS would only have to produce an annual gain of $3,800 per participant to meet a cost-benefit test. Given the scope of the benefits, that test would be passed easily.

The scheme should involve a common set of eligibility criteria, entitlements to individually tailored supports based on the same assessment process, certainty of funding based on need, genuine choice over how their needs were met (including choice of provider) and portability of entitlements across borders. There would be local area coordinators and disability support organisations to provide grass roots support. The insurance scheme would take a long-term view and have a strong incentive to fund cost effective early interventions, and collect data to monitor outcomes and ensure efficiency.

The above features would be best met by having a single agency overseeing the NDIS – the National Disability Insurance Agency. It would be created by, and report to, all Australian governments. It would have strong governance arrangements, with an independent commercial board, an advisory council of key stakeholders, clear guidelines to ensure a sustainable and efficient scheme, and legislation that protected the scheme from political influences.

It would be the assessor and funder, but not the provider of care and support. Services would be provided by non-government organisations, disability service organisations, state and territory disability service providers, individuals and mainstream businesses. Increased funding, choice and certainty are the key features of the recommended scheme. Advocacy would be funded outside the scheme.
An alternative but inferior option would be a ‘federated’ NDIS. This would give state and territory governments control over their own systems, but with some common core features. Such an arrangement could easily revert to the current flawed and unfair system, with ‘agreements’ breaking down into disputes about who is to pay, how much and for what.

People would have much more choice in the proposed NDIS. Their support packages would be tailored to their individual needs. People could choose their own provider(s), ask an intermediary to assemble the best package on their behalf, cash out their funding allocation and direct the funding to areas of need (with appropriate probity controls and support), or choose a combination of these options.

The NDIS would cover the same types of supports currently provided by specialist providers (but with sufficient funding), give people more opportunity to choose mainstream services, and encourage innovative approaches to support.

The Australian Government currently provides funding to the disability sector of around $2.3 billion, while state and territory governments provide funding of around $4.7 billion – a total of over $7 billion.

Current funding for disability is subject to the vagaries of governments’ budget cycles. People with disabilities have no certainty that they will get reasonable care and support over the long run. Resourcing might be good one year, but insufficient the next, with many people missing out. The Commission estimates that the amount needed to provide people with the necessary supports would be about double current spending (an additional $6.5 billion per annum).

People with disabilities have no certainty that they will get reasonable care and support over the long run.

The Commission proposes several options for providing certainty of future funding. Its preferred option is that the Australian Government should finance the entire costs of the NDIS by directing payments from consolidated revenue into a ‘National Disability Insurance Premium Fund’, using an agreed formula entrenched in legislation. The amount needed could be funded through a combination of cuts in existing lower-priority expenditure, fiscal drag, and if necessary, tax increases.

A less preferred option is that all governments could pool funding, subject to a long-run arrangement based on the above formula, and with pre-specified funding shares. This would need to be closely monitored by transparent accounting and penalties for failure to meet commitments.

The scheme would gradually be rolled out from mid-2014. It would start in a few regions. That would allow fine-tuning of the scheme, while providing high quality services to many thousands of people. In 2015-16, the scheme should cover all regions of Australia for the highest priority groups, and should progressively expand until the scheme covered all people by the end of 2018-19.

A separate scheme is needed for people requiring lifetime care and support for catastrophic injuries – such as major brain or spinal cord injuries. Currently, many Australians get poor care and support when they acquire such injuries because they cannot find an at-fault party to sue.

A no-fault National Injury Insurance Scheme, comprising a federation of individual state and territory schemes, would provide fully-funded care and support for all cases of catastrophic injury. It would draw on the best schemes currently operating around Australia. State and territory governments would be the major driver, developing a comprehensive scheme by 2015.
Carers Australia is the recognised national voice of Australian carers. Our members are the carers associations in each state and territory. We have no political affiliation. We work with all parties to achieve better outcomes for all carers. We believe that all carers are entitled to the same rights, choices and opportunities as other Australians. The NDIS has the potential to vastly improve the lives of people with a disability and their carers.

Carers Australia welcomes the release today of both the Productivity Commission’s report, Disability Care and Support and the Government’s announcement that it will proceed immediately with measures to build the foundations for a National Disability Insurance Scheme (NDIS).

For far too long carers have felt undervalued by the service system and not engaged in the reform process.

Carers Australia’s President Tim Moore said, “with these developments there was now great hope in the community that Australia would at last introduce a scheme that would provide quality care and support to all people with a significant disability. Not only would this be of immeasurable benefit to the estimated 410,000 Australians with disabilities that would be covered by the scheme, but it would also ease considerably the burden of support provided by their carers. Mr Moore said there are hundreds of thousands of carers who make an enormous contribution to the Australian community by supporting family members and friends with a disability. This contribution is often unseen and involving considerable personal commitment which may negatively affect their own health, wellbeing and community connectedness.”

Carers Australia gave strong support to the key recommendations for the introduction of a NDIS contained in the Productivity Commission’s draft report released in February. Mr Moore was particularly pleased that in its final report the Commission has expanded the coverage under the scheme of people with a disability caused by mental illness. “It is right and just”, he said that “people with these disabilities have been included in the proposed scheme on a similar basis to people with other types of disability.”

Mr Moore remarked on the potential of a NDIS to facilitate greater participation of carers in the workforce. To ensure that this potential is realised it will be important that government provide training and other assistance to help carers return to the workforce or to move into more demanding jobs.

The Productivity Commission report states that it will take at least seven years to fully implement a NDIS. If full implementation is to be achieved, Mr Moore said “it will be critical that a NDIS receive broad community support and from all political parties, including at the state and territory level. It will only be with widespread support that the nation can be confident it can achieve such profound change.”

For far too long carers have felt undervalued by the service system and not engaged in the reform process. Carers Australia strongly urges the government to provide ample opportunity for carers to participate in the development and implementation of a NDIS.
What is the most remarkable aspect of this report?

The Productivity Commission is proposing an important set of reforms with its *Caring for Older Australians* report.

These reforms chart a way to cut through a funding knot that has prevented us from moving ahead with effective and integrated aged care funding.

Since the mid-1990s, we’ve only been able to fund the capital cost of residential care for low-care units because there are political obstacles to requiring or even allowing older people to make a capital contribution to their residential accommodation.

The argument was that the public sector should pay for it – it should be like going into a public hospital.

So we’ve got an aged care industry that’s starved of capital for nursing home-type accommodation.

That’s the knot and it’s resulted in high-level residential care drying up because it’s difficult to fund the building of new units.

This means that people haven’t been able to get access to high-level care even if they could pay for it.

What this proposal does is make funding much more equitable, much more transparent and much more effective.

What the ‘Caring for Older Australians’ report means for the future of aged care

THE POINT IS TO PROVIDE ADEQUATE AND EQUITABLE CARE, SAYS HAL KENDIG

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What this proposal does is make funding much more equitable, much more transparent and much more effective.

So how will financing of aged care accommodation change?

One of the options that people can take, if they have the means, is to pay an accommodation bond, which means they contribute their own money up to a certain amount.

This bond is returned to them or their heirs according to a formula that will take into account how long they’ve been in care and other factors. It means they are loaning the provider money to cover capital costs.

One of the ways people could do this is through the use of the equity in their home but they don’t have to sell their home. What they will have to do is to accept that the size of their estate will be smaller when they die because some of it will go into paying for their care.

People can also choose to pay daily charges for the capital costs as an alternative to making an accommodation bond, and government can meet the costs on a means-tested basis for those who cannot pay themselves.

There will be lots of options and choices for mixing private money and public money in an equitable way and that will bring investment back into the industry that’s been very difficult to raise for more than a decade.

Accommodation costs and living costs are going to be means tested in the same way as the age pension is means tested. Until recently, we haven’t been means testing the accommodation part of high-level residential care – it’s all been bundled into the nursing home or else paid for privately to hostels.

The Productivity Commission is proposing ways to separate out these kinds of support and equitably determine who is responsible for paying for what.

Means testing will not be carried out by the individual aged care providers; it’ll be done basically the same way as the means test on the aged-care pension.

One of the most important things in this report is that it separates accommodation costs, living costs and care costs. This will give people more choice about their care arrangements, including more flexible capacity to stay in their own homes.

How will this change the way older people access care?

Right now, the only way you can access highly subsidised aged care is by going into a nursing home but a lot of older people won’t go because they don’t want to live in an institution – for many, it means losing their identity.

But if you unbundle or separate the accommodation and the care part, then you can mix and match and fit it together to suit your own needs.

So, you could more easily stay at home and get a high level of care – that’s what this report makes provisions for. So you could meet your private costs for accommodation,
even pay more if you can (if you want higher levels of accommodation), and still get a large public subsidy for your care on the basis of your needs. You could have mixed-care support from your caregivers and your own self-care can play a part too, which is also really important. Or you could access care in the community or residential care with a public subsidy and your co-contribution would still be limited.

**What sort of resistance can we expect to implementing the report’s recommendations?**

Some consumer groups understandably don’t like the idea of older people potentially encumbering the value of their home to pay part of their care. They don’t even like it if it’s means tested or minimised. The home is very emotively important and many older people understandably want to be able to leave all of their assets as an inheritance for their children, which of course is totally tax-free.

The same issues came up when we started to asset test the aged pension back in the early 1980s and now, at a time of financial stringency, at a time when aged care needs more investment, we’re proposing to apply means testing to accommodation and care. The objections are also partly because some of us have quite idealistic views of what government should do – why can’t we just pay for all of our aged care from taxes in the way that we pay for public hospital care, for instance by bulk-billing Medicare?

Well, because we don’t have the public money to pay for all of it and it’s quite inequitable to ask all taxpayers of all ages, even those on modest earnings, to pay for accommodation and care for people who could meet more of their own costs.

How much should taxes subsidise older people who have very large amounts of wealth in their homes and who are otherwise just going to leave it to their heirs?

And why should poor older people have less access to accommodation and aged care because governments must severely ration expenditure?

The point is to provide adequate care and provide it equitably and the report has put together quite a comprehensive and carefully thought through package that manages to address the hard finance questions. These questions are tough but they need to be answered before many more baby boomers reach old age.

**Hal Kendig is Professor of Ageing and Health and Director of Ageing, Work and Health Research Unit, University of Sydney.**

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**CARING FOR OLDER AUSTRALIANS**

**Key points from the Productivity Commission inquiry report**

- Over 1 million older Australians receive aged care services. The range and quality of these services have improved over past decades, but more needs to be done.
- Future challenges include the increasing numbers and expectations of older people, a relative fall in the number of informal carers, and the need for more workers. By 2050, over 3.5 million Australians are expected to use aged care services each year.
- The aged care system suffers key weaknesses. It is difficult to navigate. Services are limited, as is consumer choice. Quality is variable. Coverage of needs, pricing, subsidies and user co-contributions are inconsistent or inequitable. Workforce shortages are exacerbated by low wages and some workers have insufficient skills.
- The Commission’s proposals address these weaknesses and challenges and aim to deliver higher quality care. The focus is on the wellbeing of older Australians – promoting their independence, giving them choice and retaining their community engagement. Under this integrated package of reforms, older Australians would:
  - Be able to contact a simplified ‘gateway’ for: easily understood information; an assessment of their care needs and their financial capacity to contribute to the cost of their care; an entitlement to approved aged care services; and for care coordination – all in their region receive aged care services that address their individual needs, with an emphasis on reablement where feasible
  - Choose whether to receive care at home, and choose their approved provider
  - Contribute, in part, to their costs of care (with a maximum lifetime limit) and meet their accommodation and living expenses (with safety nets for those of limited means)
  - Have access to a government-sponsored line of credit (the Australian Aged Care Home Credit scheme), to help meet their care and accommodation expenses without having to sell their home. A person’s spouse, or other ‘protected person’ would be able to continue living in that home when an older person moved into residential care
  - Choose to pay either a periodic charge or a bond for residential care accommodation
  - If they wish to sell their home, retain their Age Pension by investing the sale proceeds in an Australian Age Pensioners Savings Account
  - Have direct access to low intensity community support services
  - Be able to choose whether to purchase additional services and higher quality accommodation.
- Limits on the number of residential places and care packages would be phased out, while distinctions between residential low and high care and between ordinary and extra service status would be removed.
- Safety and quality standards would be retained. An Australian Aged Care Commission would be responsible for quality and accreditation; and would transparently recommend efficient prices to the Government.

*Caring for Older Australians, Inquiry Report no. 53, Productivity Commission | www.pc.gov.au*  
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NEW WAYS OF THINKING ABOUT CARE, AND CARERS

Aged care is a bit like the proverbial iceberg – the visible part above water gets all the attention, writes Michael Fine.

The Productivity Commission submitted their final report Caring for Older Australians to the Assistant Treasurer on June 28. The government is required to table the report in parliament within 25 sitting days of receiving it. For those in the know, the wait is on.

We don’t know exactly what is in the report but can be confident that the emphasis will be on the paid and formal part of the aged care system. How will the services Australia will need in the future be paid for? How will they be organised? What will happen to our jobs and our careers?

Aged care is a bit like the proverbial iceberg – the visible part above water gets all the attention. All those services and proprietors groups struggling to be heard make sure this is the case. But like the unseen seven eighths of the iceberg under water that keeps the visible bit afloat, so too is aged care sustained by an invisible and unpaid workforce: the family carers and alongside them, the volunteers. While we wait for the PC’s report and the government’s response, it is a good time to think again about their future.

Thinking anew about carers and caring was a big part of a conference in which I recently took part, held in Toronto, Canada. It was set up, ambitiously, as the Festival of International Conferences on Care, Ageing, Disability and Technology (FICCDAT), bringing together speakers from across the world and from our different specialities with the aim of cross-fertilising each of the separate fields and stimulating new ways of thinking about the issues we face daily and have come to understand as obstacles. For those that are prepared to open their minds, there were lots of lessons to be learnt.

One of the most important is about the link between paid and unpaid care. In Australia, we already know that we can’t think of them as alternatives. We need to think of them together, how they support each other and how they can work together. A message I carried home concerns the right to refuse care. To make sure that those who need care, as well as those who give it are treated inclusively, we need to find solutions that ensure that we will have the right to receive appropriate and expert care when we need it. We must also be able to assume the responsibility to give care when we seek to do so. And we must also have the opportunities and ability to care for ourselves and to take charge of our own lives as far as possible, at all times.

But I also brought home new questions. If we should all think of ourselves as carers with the rights to give care when it is needed (I’m speaking to the Aussie blokes here, not just the women) what about the responsibilities of those who receive care? Does someone in need of support have a right to refuse services? Who should decide in such cases anyway? This philosophical and ethical question was raised by the NY philosopher Eva Kittay at the beginning of the conference. If our refusal to accept help has consequences for others, she argued, surely we must accept that we have a responsibility to accept the help that is offered.

Demographers have long pointed out the coming shortage of family carers: Where will carers come from in a time when low birthrates mean there are far few adult children in any family? When divorce and family breakup have become more prevalent? Will the ‘ex’ take on the duties? How about the step-children or our close friends? This is no longer an issue to be faced in the future. It’s already with us today. New research in the UK and elsewhere seems to show that, surprisingly, these larger networks of family and friends are stepping in, in many cases. Will the same thing happen here? And if we see them, will that be as carers or volunteers?

There are new questions about technology, too. So far care seems to be delivered almost exclusively in person, but might new inventions change this? To date, much of the emphasis seems to be on the development of Assistive Technology (AT) for people with disabilities, but we too have to ask how such innovation might help us in aged care. One of the most immediate changes I think we’re likely to experience is the impact of social networking software as an organising tool for carers, services and those who depend on them. This has already taken off in the resource starved world of disability support in North America. How long will it be before we take it up here as well?

Altogether, thinking about care and carers is enough to make you wonder whether the PC report will still matter in another 25 sitting days.

Associate Professor Michael Fine is head of the Department of Sociology and deputy director, Centre for Research on Social Inclusion, Macquarie University.

Aged Care INsite. July/August 2011 | www.agedcareinsite.com.au
**Working with and supporting informal carers**

Supporting family or ‘informal’ carers is an increasingly important part of providing community care. More programs are being designed directly for carers, and finding the best ways to support them in a joint approach to care and support is a growing challenge for all service providers. A briefing prepared by the Centre for Health Service Development and the Benevolent Society

This briefing reviews some key facts about carers and the research on what works for them in terms of effective service responses. Its focus is carers of older people, and carers who are themselves ageing.

**WHO ARE CARERS?**

In the context of community care, a carer is a person who, through family relationship or friendship, looks after a frail older person or someone with a disability, chronic illness or mental illness on an unpaid basis.

Comprehensive information about Australian carers is collected through the Survey of Disability, Ageing and Carers, a national survey conducted by the Australian Bureau of Statistics (ABS 2005). It is estimated that in 2003 there were 2,56 million Australians providing unpaid assistance of one type or another, or 12.9% of the Australian population.

Most carers are middle-aged (35 to 54) and over three quarters are of working age (18 to 64 years of age). There were also 169,900 young people (under 18) who were carers, with 2,900 being primary carers. The majority of carers are female (54.1%). However, among carers aged over 65, the picture is reversed and a higher proportion are men (53.0%). Among primary carers, women predominate at all ages although among those aged over 65, 42% are men.

An estimated 450,000 carers are aged over 65 and may themselves be frail or have a disability or chronic illness.

**HOW WE THINK ABOUT CARERS**

The concepts and language commonly used in the carer support sector have been changing over the past decades. As well as distinguishing ‘formal’ (i.e. paid providers of care services) from informal care (i.e. care by a family member or friend), there has been increased recognition of carers also having needs to be met in their own right (Ramsay et al. 2007). Carers are also being acknowledged as the experts in their own lives, and for the detailed and day-to-day knowledge they have of the person they are helping. Services are being encouraged to see carers as in charge of the situation most of the time, often 24 hours a day, and to see professionals and care workers, who may be present for a few hours per week, as a secondary ‘add-on’ support.

**TABLE 1: CARERS BY AGE AND GENDER, AUSTRALIA (000s) (ABS 2005)**

<table>
<thead>
<tr>
<th>AGE GROUP</th>
<th>&lt; 18</th>
<th>18-24</th>
<th>25-34</th>
<th>35-44</th>
<th>45-54</th>
<th>55-64</th>
<th>65-74</th>
<th>75+</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary carer male</td>
<td>1.4</td>
<td>3.1</td>
<td>9.0</td>
<td>17.7</td>
<td>32.2</td>
<td>25.0</td>
<td>22.9</td>
<td>24.9</td>
<td>136.2</td>
</tr>
<tr>
<td>Primary carer female</td>
<td>1.5</td>
<td>12.6</td>
<td>5.1</td>
<td>65.6</td>
<td>83.4</td>
<td>74.8</td>
<td>38.6</td>
<td>26.8</td>
<td>338.4</td>
</tr>
<tr>
<td>All Primary Carers</td>
<td>2.9</td>
<td>15.8</td>
<td>44.1</td>
<td>83.4</td>
<td>115.6</td>
<td>99.7</td>
<td>61.5</td>
<td>51.6</td>
<td>474.6</td>
</tr>
<tr>
<td>All carers male</td>
<td>87.5</td>
<td>90.9</td>
<td>140.3</td>
<td>196.5</td>
<td>219.3</td>
<td>195.6</td>
<td>139.6</td>
<td>105.0</td>
<td>1,174.6</td>
</tr>
<tr>
<td>All carers female</td>
<td>82.4</td>
<td>86.9</td>
<td>177.0</td>
<td>288.3</td>
<td>301.7</td>
<td>237.0</td>
<td>129.4</td>
<td>79.6</td>
<td>1,382.3</td>
</tr>
<tr>
<td>Total carers</td>
<td>169.9</td>
<td>177.8</td>
<td>317.2</td>
<td>484.8</td>
<td>521.0</td>
<td>432.7</td>
<td>269.0</td>
<td>184.6</td>
<td>2,557.0</td>
</tr>
</tbody>
</table>

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Issues in Society | Volume 342

Carers: Ageing and Disability
Carers often have to manage multiple roles – as a carer and paid worker, as a carer and parent, or as both carer and being ‘cared for’ at the same time. Population surveys also show that some people prefer to see themselves as a husband, wife, son or daughter, rather than as a carer. Caring is not always seen in negative terms, but can provide a deep sense of meaning and purpose for the carer.

**ASSESSMENT OF WHAT CARERS NEED**

While the specific needs of carers will differ in each situation, evidence suggests there are many similarities to be considered during assessment of carers’ needs. Carers are likely to be concerned about financial and emotional costs, the future prospects of the care recipient (especially if the carer is not around), the need for practical assistance and more confidence, and ‘time out’ for themselves.

An initial assessment of carers’ needs will involve identifying:
- Whether a person sees themselves as a primary carer
- How much support they expect in their carer role
- For what activities of daily living their care recipient needs a carer.

Other factors to take into consideration include:
- Gender and age of the carer and care recipient
- Whether the carer’s own functional abilities
- The intensity and duration of caring
- Whether they have single or multiple caring responsibilities
- Other roles they perform and responsibilities they have (Eagar et al. 2007).

A broad but shallow screening process allows for early detection of problems, followed by timely and relevant interventions.

**DIFFERENCES IN CARER NEEDS**

Although there are more similarities than major differences between the carers of different types of care recipients (Eagar 2007), some differences in the need for support and practical assistance do arise from the particular characteristics of the care recipients.

For example, carers might be:
- Facing the emotional pressures of dealing with challenging behaviour in people with dementia
- Experiencing grief due to the expected death of the care recipient
- Dealing with complex technical tasks in caring for the chronically ill
- Dealing with the unpredictable nature of mental illness.

Providing effective support means being able to assess the carer’s needs and strengths in whatever domains are relevant to their circumstances.

**Changing needs over time**

The needs of carers may change

<table>
<thead>
<tr>
<th>DOMAINS OF CARER ASSESSMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caring context</strong> – where the caring takes place, how often, what other services are used, and the carer’s relationship to the care recipient.</td>
</tr>
<tr>
<td><strong>Functional level of care</strong> – the activities of daily living that the carer helps with and how this relates to the level of the care recipient’s independence.</td>
</tr>
<tr>
<td><strong>Health</strong> – the carer’s own health and wellbeing, as well as the health and wellbeing of the care recipient.</td>
</tr>
<tr>
<td><strong>Financial, legal and employment</strong> – the carer’s financial and employment situation, access to benefit entitlements, the legal relationships and obligations to the care recipient, like power of attorney, financial management and guardianship.</td>
</tr>
<tr>
<td><strong>Confidence and competence</strong> – the carer’s skill level and confidence in performing the required caring tasks, including any medical tasks like giving medication or using equipment, or physical tasks like lifting.</td>
</tr>
<tr>
<td><strong>Positive aspects of caring</strong> – how the carer feels about the situation and what the carer gets out of it.</td>
</tr>
<tr>
<td><strong>Knowledge</strong> – the carer’s knowledge of available support options for themselves and the care recipient, like respite care.</td>
</tr>
<tr>
<td><strong>Social support</strong> – the carer and care recipient’s support networks including friends, family, community groups and services like transport and shopping.</td>
</tr>
<tr>
<td><strong>Coping strategies</strong> – how the carer copes with the situation and what, if anything, might place the situation at risk of breakdown.</td>
</tr>
<tr>
<td><strong>Values and preferences</strong> – including cultural and religious values and beliefs that reflect on the situation.</td>
</tr>
<tr>
<td><strong>Strengths and risks</strong> – areas where the carer is doing well, and areas where they need support – the kind of support that would make the biggest difference for the future.</td>
</tr>
</tbody>
</table>

**CHANGES IN THE FOCUS ON CARING**

Over the years, the way that services have thought about carers has been changing. The table below shows the main focus of each period.

<table>
<thead>
<tr>
<th>Period</th>
<th>Focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>1960s</td>
<td>Carer burden, the impact of caring on carers’ mental health, physical health, other family relationships, employment and financial problems.</td>
</tr>
<tr>
<td>1980s</td>
<td>Stress models, mastery, role overload, role captivity.</td>
</tr>
<tr>
<td>1990s</td>
<td>Multiple impacts of caring. Positive aspects of caring, with strengths and resilience models emerging.</td>
</tr>
<tr>
<td>Late 1990s</td>
<td>Carers as ‘clients’, with needs to be met in their own right.</td>
</tr>
<tr>
<td>2000s</td>
<td>Carers as joint partners – with the care recipient, with formal services and as a recipient of support services – and where the aim is to ‘personalise’ care.</td>
</tr>
</tbody>
</table>
over time as the care recipient becomes better able to function, or conversely develops different, more complex or intense needs.

If we are helping carers to plan for the longer term we may also be interested in their transitions into and out of the workforce. Understanding the impact on the carer of beginning, changing, continuing or ending their informal care role will be relevant to providing a personalised service.

Access to flexible working hours, a range of affordable formal support services and being able to share the load with other family members can help women in particular in continuing in their caring roles (Berecki et al. 2008).

OPTIONS FOR SUPPORTING CARERS

The options for supporting carers have expanded greatly in the past two decades, especially due to the advent of dedicated programs for respite and for access to information. The growth of carer advocacy bodies has meant that the pressure for continued improvements and expansions to services has also grown. Carer support programs can be grouped into several types, each with differing challenges and evidence of effectiveness:

Information resources

There is now a great deal of information available about support services and counselling, self-help and condition-specific groups in local communities, operating through neighbourhood centres, local councils, community health and aged care agencies (Commonwealth Respite and Carelink Centres 2010). However, evidence suggests that giving information alone (whether verbal, printed or online) is not effective. Teaching specific skills like medication management or dealing with problem behaviour is better practice.

Carer support groups

Support groups give carers an opportunity for mutual support from other people in similar situations. There is emerging evidence that support groups may be helpful for carers of CALD backgrounds, carers of children with disabilities and carers of people with mental illness. Carer support groups can be a good source of emotional support and information and can help reduce the sense of isolation.

Family support

Family support interventions are delivered in the home and focus on role modeling, problem solving, coaching and emotional and practical support. Reviews of family support services for people with a mental illness conclude that family support interventions are effective.

Education

Educational interventions focus on increasing carers’ knowledge about their care recipient or situation. For example, dementia education can help carers understand behavioural issues, learn stress management techniques and manage medication. The overall evidence on educational interventions is good, especially for carers of people with dementia, mental illness and disability.

Counselling

The overall evidence on counselling interventions is positive. However, there is little evidence on the effectiveness of different types of counselling or on ‘how much’ is needed to be effective. Some studies and reviews report no measurable 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.

Case management and care coordination

Case management and care coordination interventions increase and streamline carers’ and care recipients’ access to support and services. The small number of studies investigating case management and care coordination and their impact on the carer, show promising evidence of being effective. Benefits included

BARRIERS TO THE USE OF RESPITE

Even where respite care is available, carers may not use it. For example, carers of people with dementia have identified respite care as one of their critical care needs, but their low use of residential respite care does not reflect this. Only about a quarter (27%) of people approved for residential respite care actually used it within 12 months of receiving approval. Carers described barriers such as local shortages of respite places, affordability, insufficient flexibility in respite care options and difficulties in understanding and accessing available services (AIHW 2010).

Carers’ attitudes towards respite care also influence whether they will use it. Among carers of people with dementia, attitudes regarding the perceived utility and quality of respite services accounted for more of the differences in how carers use services than either carer or care recipient need (Kosloski and Montgomery, 1993). Likewise more recent research with Australian dementia carers (Phillipson, Jones and Magee, 2010) suggests that carers’ beliefs about service outcomes (e.g. that they will be negative for the care recipient) are stronger predictors of which carers will use respite than their assessed need (e.g. burden or depression scores). Carers who believe that outcomes associated with respite use will be negative may actually start with the intention of not using it (Phillipson and Jones, 2010).

This highlights the importance of initial assessment and ongoing monitoring in identifying and understanding the factors that may prevent a carer from using services.
reduced carer stress, reduction in hospitalisation and an increase in carer satisfaction.

**Respite care**

Various types of respite care are available: in-home, residential, centre-based, and host families. To date, the overall research evidence is that respite care can provide small benefits. One study found that while it does not relieve carer burden or improve mental health, carer satisfaction with the service was high. Other studies found that respite resulted in reduced stress and emotional distress. Some studies and reviews report no measurable effects, although this could be due to methodological problems in the research or real world factors like the respite being hard to use or not tailored to the carers’ cultural expectations (Eagar et al. 2007).

**Multi-component interventions**

Multi-component interventions incorporate a variety of components such as skills training, information and referral, respite, and counselling. There is good evidence for the effectiveness of multi-component interventions. Benefits included positive effects on carer burden, wellbeing and knowledge.

A good fit between the carers’ stated or assessed needs, and the goal of the service to be provided, is not always easy to achieve. Care agencies need to find the right mix of carer support interventions and the best time to provide them. Is the service mainly geared to benefit the carer, or the care recipient, or both? Is it expected to achieve something in the short term to fix an immediate problem, like training on better management of a person’s problem behaviour, equipment for lifting or bathing, or assistance with medication management? Or are longer-term impacts more likely?

**CHALLENGES IN CARER SUPPORT RESEARCH**

Because of the community sector’s complexity, the results from evaluation research and systematic reviews of the literature on existing programs (such as educational interventions, respite services, support groups) have not been very conclusive (Eagar et al 2007, Williams and Owen 2009).

It is also difficult to conduct rigorous evaluation studies of community support interventions when these vary so much in their design and implementation, and because denying a potentially beneficial service to a control group presents ethical issues.

So it is not surprising that much of the evidence about what works best for carers is not of gold standard quality or that the results are sometimes unclear. However, it should be emphasised that a lack of good evidence for whether an intervention is successful is not the same as evidence of its ineffectiveness.

We do know that individual approaches are more likely to have significant effects in terms of improving carer wellbeing than those based on group approaches. This is because individual sessions can be better targeted, more personalised and more intense.

We also know that some services offered to carers do not seem to have an impact on carer burden; that is, the interventions are not therapeutic in the sense of reducing a carer’s score on a particular burden scale in the short term. Nevertheless, such services may be preventive or protective, for example they may increase the carer’s capacity and resilience, build self-worth or enhance social support. So a carer might feel better, although no less burdened, or may be more capable of staying in the caring situation for longer (Sørensen et al. 2002).

**MEASURING CHANGE**

When we talk about effective interventions, this implies that the expected outcomes have been defined and can be measured. In order to measure change (or lack of change) over time, practical measurement tools are required.

Some assessment items and scales in current use include:

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**DISCUSSION GUIDE**

1. People in a caring role won’t always identify as a ‘carer’. How might the use of language impede or encourage the engagement of carers?
2. Describe a best practice approach to assessment and referral that ensures the needs of both carers and care recipients are identified and addressed.
3. People from diverse cultural backgrounds have many different approaches, roles and expectations when it comes to informal care. Discuss what this means for us in the provision of formal support to carers.
4. How might service providers put more focus on resilience building and holistic support so that carers can feel more equipped to manage adversity? What does strengths-based service delivery ‘look like’ when we work with carers?
5. Using real practice examples, explore the role that broader informal support networks play in supporting care recipients and carers. As service providers, how do we empower and facilitate the development of informal support networks?
6. In Aboriginal and/or Torres Strait Islander communities, extended families and other community members often play a greater role within informal care arrangements. How would you go about finding out about existing care arrangements and providing culturally respectful support?
7. What could be some of the reasons a carer is resistant to support? Based on the reasons identified, how might you go about building trust and/or providing person-centred care in this context?
8. What would be your approach to supporting an older couple, both in poor health, caring for each other?
9. At times, the needs and interests of a carer and a care recipient may be in contradiction. Can you think of examples of this? How do we effectively identify and manage these tensions? How do we ensure that the rights and choices of the care recipient are upheld in the provision of formal service support (such as respite) to carers?

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Thanks to Community Care (Northern Beaches) for their assistance with these discussion questions.

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44 Carers: Ageing and Disability

Issues in Society | Volume 342
**Carer health, wellbeing and function:**

Twelve items cover self-reported health status, bodily pain, mental health and wellbeing functional ability scores (i.e. the SF36, K10, HACC Screen).

**Continuity of relationships between formal and informal carers:**

The best indicators are three items: evidence of a carer having a role in care planning and service delivery; the carer’s relationships with service providers; cooperation with treatment.

For more information and sources of measurement scales and assessment tools see the References list on the Benevolent Society website: www.bensoc.org.au

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**EMERGING ISSUES IN THE CARER SUPPORT SECTOR**

In the most recent UK social policy thinking, carers are now seen as joint partners in caring – with the care recipient, with formal care and as a recipient of support services in their own right – and where the overall aim is to achieve the right mix and to personalise care (Limbery 2010).

In Australia, a variety of service delivery models reflect this same shift, towards ‘consumer-directed care’. Under these models, a case manager may arrange services on behalf of a client, or the client and/or the family or carer receives funds to purchase services themselves (Australian Department of Health and Ageing 2010).

The growth of ‘enabling’ and ‘strength-based’ models also reflect a concern for supporting more personalised, capacity building and consumer controlled service models. Good examples of these models exist at different stages of evolution in most states and territories, such as in the Victorian community care sector’s HACC-based Active Service Model (Victorian Department of Health 2010, Western Australia Silver Chain 2010, NSW IMPACT Services 2010).

The intention to give more control to care recipients and carers over the type of services they receive and the goals they wish to achieve has been a recognised feature of service provision for many decades (Ozanne 1990) but there is validity in the idea that all services should continually strive to move their daily practice in the direction of more consumer-friendly carer support interventions.

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**SOME USEFUL RESOURCES**

- Carers Australia: www.carersaustralia.com.au
- Alzheimer’s Association: www.alzheimers.org.au
- Commonwealth Respite and Carelink Centre: www.commcarelink.health.gov.au

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**PRACTICE IMPLICATIONS**

**Know the carer and the care recipient** and plan in partnership with them. All carers and care recipients are individuals and what they need in order to lead fulfilling and active lives will differ.

**Think of assessment as a continuous process.** Carer and care recipients’ needs will change over time. Each meeting with a carer is an opportunity to understand more about the complexity of the caring arrangements. It is a chance to ask whether other supports are needed, and to consider what would work best in the particular circumstances of this carer and of this care recipient.

**Talk about the barriers to service access.** If carers expect the outcomes of services, such as respite, to be positive they are likely to accept them. Some carers’ fear of what will happen if someone other than themselves provides care to the care recipient may be a huge obstacle. In such circumstances, carers are likely to require support and evidence to persuade them that the use of respite services will in the long run (if not immediate term) be positive, not only for themselves, but also for the care recipient.

**Give carers the chance to do things for themselves.** Care workers may be tempted to step in and help out with complex problems but should also consider approaches that will help carers become less reliant in the longer term. Getting the right mix of useful interventions, while actively encouraging clients and their carers to do as much for themselves as possible, is the aim. However this should be balanced with recognition that many will need continuing practical support to prevent further decline in their abilities.

**Talk to carers about the full range of their support options** – not just the ones you have to offer in your service. Describe the different types of respite, support groups, training, counselling and Centrelink payments etc. Find out about possible sources of additional help within their own family and local networks.

**Support carers’ own health.** Talk about and offer information and support around the carer’s health. Carers often think that their health needs are secondary to those of the person they assist.

**Acknowledge carers’ expertise.** Carers are the direct link to the experiences of the person to whom they are giving care. Explicitly acknowledging their expertise and knowledge of the person they looking after is part of building a carer’s confidence and resilience.

**Work with carers to set and review achievable goals.** Work alongside the clients, their carers and families to plan what support is required to enable them to maintain their independence and work towards their personal goals. Review the situation regularly to check whether the goals in the care plan have been met. But checking on progress should not be too cumbersome. Depending on the circumstances, this may involve a follow-up phone call or a fuller re-assessment.

**Listen to carers’ feedback** on the ways that services could be improved to better meet their needs and those of care recipients. For many services ‘drop out’ rates are quite high. In addition to identifying whether a carer’s goals have been achieved, there may be a need to identify any obstacles encountered in attempts to use recommended services.
Palliative Care Australia is the national peak body established by the collective membership of eight state and territory palliative care organisations and the Australian and New Zealand Society of Palliative Medicine. Together the Palliative Care Australia members network to foster, influence and promote local and national endeavours to realise the vision of quality care at the end of life for all.

Palliative Care Australia believes

➤ Dying is part of life. The care of people at the end of life, their families and carers is the responsibility of the whole community

➤ Carers must be recognised as both a key partner in the care team and a recipient of care in accordance with the palliative care service provision model

➤ Enabling people's preferences to receive quality care at the end of life in the setting of their choice is dependent upon ongoing physical, emotional, practical and spiritual support from individual carers and their communities as well as health professional support

➤ The extent and quality of support provided to the carer and the person nearing the end of life is a key determinant of both of their experiences. The whole community should support them

➤ As a community we can and must do better in supporting carers by developing the foundations of a carer-supportive social system that provides the necessary support to enable carers to provide care in a manner that also promotes their health, wellbeing and personal aspirations.

Palliative Care Australia calls for

➤ The role of carers in providing and enabling quality care for people nearing the end of life to be recognised and valued by society

➤ Provision of greater information and support to carers and to patients to enable them to access health care and carer support services, aided by greater links between services

➤ Commitment to developing the foundations of a carer-supportive social system that supports and enables carers by:

   - Providing improved access to timely in-home support (including services, equipment, information, education and resources)
   - Developing and implementing best practice models for delivering nationally consistent carer education and training
   - Providing expanded access to respite care services to support carers
   - Promoting the health and wellbeing of those caring for people at the end of life by educating primary health care providers in the early identification of carers' emotional and physical health needs, including during bereavement; encouraging regular health checks for carers; and ensuring that carers have timely access to counselling services, including during bereavement
   - Addressing carers' needs for greater financial support, and
   - Supporting participation of carers in the labour force through carer-sensitive workplace policies that support flexible working hours and leave arrangements for carers.

Adequate support is not a reality for many carers. This is associated with physical, emotional and financial costs to their wellbeing.

Background

There are close to 2.6 million carers, and nearly 500,000 primary carers in Australia, providing close to 1.2 billion hours of care annually. Estimates suggest that carers provide 76% of all services to people needing care and support.

The need for care within our communities is expected to increase with the ageing of our population. This is informed by the continuing increase in life expectancy of Australians and the accompanying changing nature of the last phases of life. Congruently, with the changing nature of causes of death and increased medical interventions, there are a greater number of Australians living out the final stages of their life with chronic, complex conditions. The pragmatic reality is that many elderly Australians may live extended periods of time with disability and as the recipients of informal care.

Associated with the increasing need for end of life care is an expected ongoing decline in the caregiver ratio. The ratio of primary caregivers to older persons needing informal care is estimated to drop from 57/100 to 35/100 in the next thirty years.
Improved services such as respite are presently needed to support carers in their diverse roles.1 These services will need to be further upgraded and extended as the numbers of carers decrease in the future.

**Needs-based service provision**

In 2005, PCA endorsed a population needs-based approach to end of life care service development which articulated a plan for providing equitable access to end of life care while promoting effective and ethical use of resources8. PCA recognises population needs-based end of life care as a quality management approach that involves the evaluation of individual holistic needs of patients, their families and carers and provides for the coordination of appropriate care.

The 13 Standards for Providing Quality Palliative Care for all Australians9 define the standard of care that all Australians should be able to expect in different care settings.

For the purposes of population needs-based service planning, all people at the end of life can be considered to fall within three broad subgroups – those whose care needs can be categorised as:

- Complex, or
- Intermediate, or
- Appropriately addressed through primary care services.

Patients may need to move at different times between these subgroups. This should be as seamless as possible.

**Carers and end-of-life care at home**

An estimated 100,000 Australians die each year from an ‘expected’ death.10 Each of these Australians should be able to rely on a promise of access to quality care at the end of life that is based around meeting their needs and respecting their care preferences.

Many Australians express a preference for their home to be the primary site of their end-of-life care if circumstances allow.11 Supporting people’s preferences to receive end-of-life care in their home is, in many cases, dependent upon ongoing physical, emotional and spiritual support from the community, and, most often, from individual carers.

**Support and the caring experience**

Caring for someone who is dying is an individual commitment and can be a rich, rewarding and challenging personal experience. Carers often express strong positive emotions about their caregiving. Many describe an opportunity to express their love through caregiving and find significant meaning in their roles.12

The caring experience, however, occurs within a broad social context which is a key determinant of the quality of that experience. Carers’ caregiving experience, health and wellbeing are inextricably linked to the availability and quality of the support they receive. Evidence attests that those fortunate to have sufficient support mostly reflect positively on their caring experience.13 Conversely, there is considerable evidence that ongoing caregiving adversely affects family caregivers who are not sufficiently supported and lack adequate resources in undertaking this complex role.14

Adequate support is not a reality for many carers. This is associated with physical, emotional and financial costs to their wellbeing. The largest survey of carers’ health and wellbeing conducted to date found that carers have the lowest level of wellbeing of any population group.15 There is strong evidence suggesting that the physical health of carers can be adversely affected by adopting a carer role if sufficient support is not provided and that there is often a heavy emotional strain associated with caregiving at the end of life, with carers experiencing fatigue, resentment, social isolation and stress.16,17

Caregiving is often associated with a negative impact on financial security and wellbeing. The primary caring role reduces a person’s chances of being employed as caring commitments mean that some carers are unable to work, or have to work fewer hours or in a lower paid job.18 Limited employment opportunities for primary carers are reflected in their incomes, with over half reporting a government pension or allowance as their principal source of income.19 Lack of flexible working arrangements for those caring for someone who is dying or for those experiencing bereavement compound the stress often experienced by carers.20

Caregiving may have an economic burden on carers in addition to the negative impact on their employment, with significant costs incurred through medication and health care costs, fees for community services and payments towards residential care and respite.21 There are also long-term financial impacts of caring, such as loss of superannuation and the ability to save for retirement or to realise personal aspirations or goals.22

A carer both provides and needs support, yet the needs of carers are often overlooked. Carers frequently subordinate their own emotional and health needs beneath those they are caring for and these needs are frequently overlooked by health and care workers who are not trained to recognise them.23

Research undertaken by PCA has identified that carers commonly have critical unmet information and education needs relating to their carer role.24 Many carers are not equipped with adequate support, training and resources to enable them to carry out their end of life care responsibilities effectively. Capacity to meet needs directly impacts the quality of care received by the patient as well as the caring experience and quality of life of the carer.25 There are currently no long-term, nationally consistent education and training packages for carers and limited infrastructure to maintain a sustainable education and training program.26

Research undertaken by PCA suggests that many high intensity carers see respite care as the most important support service to promoting their health and wellbeing.27 Access to respite care is disparate across the nation, frequently not available in ‘emergency’ situations or on a short notice, and respite places for palliative patients are often further limited due to specific care needs and eligibility criteria.
Palliative care acknowledges the carer as both part of the care team and as a recipient of care and recognises that the needs of the carer do not stop with the death of their loved one, but include care and support to deal with bereavement and grief. However, the capacity of primary care providers who may be supporting the carer in the provision of end-of-life care to identify and address carers’ physical and emotional health needs is often inhibited by lack of awareness and education as well as systemic barriers.

**Carers and end-of-life care provision**

End-of-life care combines the broad set of health and community services that care for the population at the end of their life. Quality end-of-life care is realised when strong networks exist between specialist palliative care providers, primary generalist providers, primary specialists, and support care providers and the community – working together to meet the needs of the people requiring care.

**Palliative care** is specialist care provided for all people living with, and dying from an eventually fatal condition and for whom the primary goal is quality of life.

1. **End of life:** That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown.
2. **End-of-life care:** End-of-life care combines the broad set of health and community services that care for the population at the end of their life. Quality end-of-life care is realised when strong networks exist between specialist palliative care providers, primary generalist providers, primary specialists, and support care providers and the community – working together to meet the needs of the people requiring care.

**ENDNOTES**

1. The following definitions of end of life, end of life care and palliative care are used throughout this position paper. Source: Palliative Care Australia, Palliative and End of Life Care – Glossary of Terms, PCA, Canberra, 2008.
4. **Palliative Care Australia (PCA), The hardest thing we have ever done – the social impact of caring for terminally ill people in Australia 2004: Full report of the national inquiry into the social impact of caring for terminally ill Australians, PCA, Canberra, 2004.**
7. **PCA, The hardest thing we have ever done, 2004.**
9. **PCA, Standards for providing quality palliative care for all Australians, PCA, Canberra, 2005.**
12. **PCA, The hardest thing we have ever done, 2004.**
13. **PCA, The hardest thing we have ever done, 2004.**
14. **PCA, The hardest thing we have ever done, 2004.**
15. **RA Cummins, J Hughes, A Tomyn, A Gibson, J Woener, and L Lai, Australian Unity Wellbeing Index, Survey 16.1, Special Report – Groups with the highest and lowest wellbeing in Australia, Deakin University, Australian Unity Limited and Carers Australia, Melbourne, 2007.**
17. **PCA, The hardest thing we have ever done, 2004.**
18. **Australian Bureau of Statistics, Disability, ageing and carers: summary of findings, cat. no. 4430.0, ABS, 1998.**
19. **ABS, Disability, ageing and carers, 1998.**
20. **PCA, The hardest thing we have ever done, 2004.**
21. **PCA, The hardest thing we have ever done, 2004.**
22. **PCA, The hardest thing we have ever done, 2004.**
23. **PCA, The hardest thing we have ever done, 2004.**
24. **PCA, The hardest thing we have ever done, 2004.**
25. **PCA, The hardest thing we have ever done, 2004.**
27. **PCA, The hardest thing we have ever done, 2004.**
EXPLORING ISSUES

ABOUT THIS SECTION

‘Exploring issues’ features a range of ready-to-use worksheets relating to the articles and issues raised in this book.

The activities and exercises in these worksheets are suitable for use by students at middle secondary school level and beyond.

As the information in this book is gathered from a number of different sources, readers are prompted to consider the origin of the text and to critically evaluate the questions presented.

Does the source have a particular bias or agenda? Are you being presented with facts or opinions? Do you agree with the writer?

The types of ‘Exploring issues’ questions posed in each Issues in Society title differ according to their relevance to the topic at hand.

‘Exploring issues’ sections in each Issues in Society title may include any combination of the following worksheets: Brainstorm, Research activities, Written activities, Discussion activities, Quotes of note, Ethical dilemmas, Cartoon comments, Pros and cons, Case studies, Design activities, Statistics and spin, and Multiple choice.

CONTENTS

BRAINSTORM 50-51
WRITTEN ACTIVITIES 52
RESEARCH ACTIVITIES 53
DISCUSSION ACTIVITIES 54
MULTIPLE CHOICE 55-56

WORKSHEETS AND ACTIVITIES
Brainstorm, individually or as a group, to find out what you know about informal caregiving in Australia.

1. What is an informal carer?

2. How do people become carers?

3. What do carers do?

4. What are the challenges of caring?
5. What are the rewards of caring?

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6. Define the following terms and consider how their meanings differ from one another.
   – Care workers:
     ______________________________________________________________________
     ______________________________________________________________________
     ______________________________________________________________________
     ______________________________________________________________________
   – Foster carers:
     ______________________________________________________________________
     ______________________________________________________________________
     ______________________________________________________________________
     ______________________________________________________________________
   – Older parent carers:
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   – Kinship carers:
     ______________________________________________________________________
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Complete the following activities on a separate sheet of paper if more space is required.

1. Carers provide informal assistance for a range of tasks to people with disabilities, long-term conditions and frail aged people. These tasks include: self-care, health care, mobility, transport, housework and property maintenance. Present at least two specific examples of each of these caregiving tasks.

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2. Carers play an important role in providing a sense of security for people requiring assistance through daily activities such as communication and social involvement, supporting the social inclusion of the aged and people with disability, co-ordinating their formal care services, and advocating on their behalf. Present at least two specific examples of each of these daily activities.

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Complete the following activities on a separate sheet of paper if more space is required.

1. Many carers are confronted by a range of challenges in their caregiving role. They may experience poor health and wellbeing, face financial hardship and social isolation, and are often not properly supported by services. Provide examples of each of these challenges for carers, and if possible, base your responses on the experiences of people you personally know who are informal carers.

2. The annual replacement value of care provided in 2010 was over $40.9 billion. It is estimated that carers provided 1.32 billion hours of unpaid care in 2010, the productivity loss of which is estimated at $6.5 billion. What might be the types of ‘opportunity costs’ borne by carers in relation to lost income associated with reduced or withdrawn employment, missed career advancement and further education opportunities? Provide two scenarios based on an individual carer’s financial challenges.
DISCUSSION ACTIVITIES

1. Young carers are people under the age of 26 who provide care in a family affected by illness, disability, mental health and/or drug or alcohol issues. Young carers provide a wide range of practical and emotional assistance to those they care for. In pairs or a group, discuss what forms of assistance young carers might provide, and what specific challenges caring roles may present for young people.

   Notes:

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2. Refer to the 10 core principles which guide the National Carer Recognition Framework (page 18). Divide your class into 10 groups, and task each group with explaining to the whole class one specific core principle, presenting key discussion points on a large sheet of cardboard, blackboard or projector, if required.

   Notes:

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Complete the following multiple choice questionnaire by circling or matching your preferred responses. The answers are at the end of the next page.

1. According to Access Economics, the annual replacement value of informal care provided in Australia in 2010 was:
   a. $6.5 billion
   b. $16.5 billion
   c. $4.9 billion
   d. $40.9 billion

2. Which of the following needs may a carer be required to help someone with:
   a. Shopping
   b. Walking
   c. Bathing
   d. Banking
   e. Sitting and rising
   f. Dressing
   g. Housework
   h. Organising appointments
   i. Grooming
   j. Gardening
   k. Transporting
   l. Toileting
   m. Preparing meals
   n. Reminding
   o. Putting to bed
   p. Eating
   q. Communicating
   r. Getting up
   s. Medications
   t. Therapy

3. Match the following terms to their correct definitions:
   a. Care worker 1. Person or family who is paid to look after children and young people in their own home, usually because the young people are unable to live with their families.
   b. Informal carer 2. Person who is paid a salary or hourly rate to look after people with care needs.
   c. Foster carer 3. Anybody who lives with and looks after a child under 18.
   d. Parent/carer 4. Person who provides the majority of the informal help needed by a person because of disability or age.
   e. Kinship carer 5. Person who provides unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail aged.
   f. Primary carer 6. Person who provides some assistance, but not the majority, to those who need help.
   g. Non-primary carer 7. Relatives or close friends who look after children and young people who are unable to live with their families.
   h. Respite care 8. A person receiving this form of care will have an active, progressive and far-advanced disease, with little or no prospect of cure.
   i. Palliative care 9. A chance for carers and those they care for to take a break – at home, in a day care centre, or in a residential care home.
MULTIPLE CHOICE

Complete the following multiple choice questionnaire by circling or matching your preferred responses. The answers are at the end of this page.

4. Nominate which of these activities are core and which are non-core activities for people receiving informal assistance. (core = C; non-core = NC)
   a. Cognitive/emotional tasks C/NC
   b. Self-care C/NC
   c. Health care C/NC
   d. Paperwork C/NC
   e. Transport C/NC
   f. Mobility C/NC
   g. Household chores C/NC
   h. Property maintenance C/NC
   i. Communication C/NC
   j. Meal preparation C/NC

5. Select the correct six (6) priority areas for the National Carer Strategy:
   a. Recognition and respect
   b. Information and access
   c. Economic security
   d. Respite care
   e. Services for carers
   f. Supported accommodation
   g. Education and training
   h. Disability assistance
   i. Health and wellbeing

6. Match the following terms to their correct definitions:
   a. National Carer Strategy
   b. National Disability Insurance Scheme
   c. National Injury Insurance Scheme
   d. Caring for Older Australians report

1. A national scheme to provide insurance cover for all Australians in the event of significant disability. Its main function would be to fund long-term high quality care and support. Other important roles include providing referrals, quality assurance and diffusion of best practice.

2. Contains a vision, an aim and six important priority areas for action; builds on what the Australian Government already provides for carers and complements reforms to improve supports provided through the aged care, disability, mental health, primary health care, hospital and community care systems.

3. Proposes a set of reforms in the aged care industry required to overcome the delays, discontinuities, constraints and shortages that currently exist, and to respond to future challenges.

4. A federated model of separate, state-based no-fault schemes providing lifetime care and support to all people newly affected by catastrophic injury. It would comprise a system of premium-funded, nationally consistent minimum care and support arrangements for people suffering catastrophic injuries.

MULTIPLE CHOICE ANSWERS

1 = d; 2 = all of them; 3 – a = 2, b = 5, c = 1, d = 3, e = 7, f = 4, g = 6, h = 9, i = 8; 4 – a = NC, b = C, c = NC, d = NC, e = NC, f = C, g = NC, h = NC, i = C, j = NC; 5 = a, b, c, e, g, i; 6 – a = 2, b = 1, c = 4, d = 3.
Issues in Society | Volume 342

Carers: Ageing and Disability

★ Over 2.9 million Australians provide help and support to a family member or friend. (p.1)
★ There are currently over 2.6 million unpaid family carers in Australia, more than 770,000 of whom are primary carers. (p.2, 16)
★ It is estimated that carers provided 1.32 billion hours of unpaid care in 2010, the productivity loss of which is estimated at $6.5 billion. (p.2, 21)
★ On average, carers spend approximately 40 hours per week providing care. (p.2)
★ It is estimated that carers of someone with a mental illness spend on average 104 hours per week in the caring role. (p.2)
★ Some carers are only 10 years of age while others are nearing 90. (p.3)
★ Caring families save the Australian community more than $40 billion per year, yet many carers are in poor health, face financial hardship and social isolation, and are not properly supported by services. (p.4)
★ 50% of primary carers are on a low income and many find it hard to cover living expenses, save money or build up superannuation. (p.6)
★ Carers have the lowest wellbeing of any large group measured by the Australian Unity Wellbeing Index. (p.6)
★ Carers often ignore their own health and are 40% more likely to suffer from a chronic health condition. (p.6)
★ Unpaid carers make up 11.2% of the population across Australia. (p.7)
★ In very remote areas a greater proportion of carers are aged 24 years or less and there are far fewer carers aged 65 years or more than in other regions. (pp.7, 8)
★ There are 380,000 people under the age of 26 providing care to a family member in Australia, including 170,600 under the age of 18. (pp.8, 12)
★ Australia’s 2.6 million unpaid carers provide services estimated at more than $30.5 billion annually, yet many remain economically and socially disadvantaged. (p.9)
★ In Australia, primary carers are most often women. (pp.9, 16)
★ The majority of female primary carers aged 30 to 64 years are out of the paid labour force. (p.10)
★ By 2050 it’s estimated that 75,000 baby boomers will have dementia. (p.11)
★ Men over 65 are more likely to be caring for a partner with dementia than women of the same age. (p.11)
★ At least 1 in 10 children in Australia has some level of care responsibility in their home. This equates to there being, on average, 2 or 3 young carers in every classroom in Australia. (p.12)
★ There are 28,000 Australians over the age of 65 years who are the primary carer for an adult child with a disability. (p.13)
★ Of older parent carers, nearly all are over the age of 65, with 1 in 5 older than 80 years. Over 80% are female and nearly half of these are widows. (p.13)
★ 1 in 40 Australians are primary carers. (p.21)
★ The number of carers, and primary carers, is increasing at 2% per annum. (p.21)
★ In 2010, an estimated 129,900 carers will not be employed due to their caring responsibilities (1.1% of Australia’s workforce). (p.21)
★ The ‘carer ratio’, of primary carers to older people with a disability, is projected to fall from 60% now to under 40% by mid-century. (p.23)
★ 4 million people in Australia (18.5%) report having a disability in 2009. (p.24)
★ Almost 9 in 10 people aged 90 and over (88%) have a disability, compared with 3.4% of those aged 4 years and under. (p.24)
★ Over two-thirds of primary carers (68%) are women. (p.25)
★ Women aged 90 years and over have a higher rate of profound or severe core-activity limitations (75%) than men of the same age (58%). (p.25)
★ The proportion of Australians involved in caring for a person with a disability or an older person declined from 13% in 2003 to 12% in 2009. (p.25)
★ The gender difference among carers is most pronounced for those aged 45 to 54 years, 16% of men and 20% of women in this age group provided care for a person with a disability or aged 60 years and over. (p.25)
★ Of all those receiving informal assistance with self-care, 51% receive this help from partners and 23% from parents. (p.26)
★ Carers and their families experience high rates of mental health problems. (p.28)
★ The risk of carers and family members experiencing a depressive episode of 6 months or more was greatest in the first year of caring. (p.28)
★ Almost twice as many carers are in poorer physical health than the general population. (p.29)
★ Almost 1 in 3 female carers aged 50 or less had separated or divorced since they started caring. (p.30)
★ 13% of primary carers care for 2 or 3 people with a disability. (p.30)
★ The Australian Government currently provides funding to the disability sector of around $2.3 billion, while state and territory governments provide funding of around $4.7 billion – a total of over $7 billion. (p.36)
★ Over 1 million older Australians receive aged care services. (p.39)
★ By 2050, over 3.5 million Australians are expected to use aged care services each year. (p.39)
★ It is estimated that in 2003, there were 169,900 young people (under 18) who were carers, with 2,900 being primary carers. (p.41)
★ An estimated 450,000 carers are aged over 65 and may themselves be frail or have a disability or chronic illness. (p.41)
★ Only about a quarter (27%) of people approved for residential respite care actually used it within 12 months of receiving approval. (p.43)
★ Carers provide 76% of all services to people needing care and support. (p.46)
Activities of daily living (ADLs)
A core set of self-care activities including showering or bathing, dressing, eating, getting in and out of bed, toileting and bladder or managing continence.

Aged care
A range of services required by older people with a reduced degree of functional capacity and who are consequently dependent for help with basic daily living activities for an extended period of time.

Carer
A person of any age who provides any informal assistance, in terms of help or supervision, to people with disabilities or long-term conditions, or older people (aged 60 years and over). This assistance is ongoing, or likely to be ongoing, for at least 6 months.

Community care
Provided to people with functional restrictions who mainly reside in their own home. It also applies to the use of institutions on a temporary basis to support continued living at home, such as community care centres and respite.

Core activities
The basic activities of communication, mobility and self-care.

Core-activity limitation
There are four levels of core-activity limitation (profound, severe, moderate and mild). These are determined based on whether a person needs help, has difficulty, or uses aids or equipment with any of the core activities. A person’s overall level of core-activity limitation is determined by their highest level of limitation in these activities.

Disability
A person has a disability if they report that they have a limitation, restriction or impairment, which has lasted, or is likely to last, for at least 6 months and restricts everyday activities. These include: loss of sight (not corrected by glasses or contact lenses); loss of hearing where communication is restricted, or an aid to assist with, or substitute for, hearing is used; speech difficulties; shortness of breath or breathing difficulties causing restriction chronic or recurrent pain or discomfort causing restriction; blackouts, fits, or loss of consciousness; difficulty learning or understanding; incomplete use of arms or fingers; difficulty gripping or holding things; incomplete use of feet or legs; nervous or emotional condition causing restriction; restriction in physical activities or in doing physical work; disfigurement or deformity; mental illness or condition requiring help or supervision; long-term effects of head injury, stroke or other brain damage causing restriction; receiving treatment or medication for any other long-term conditions or ailments and still restricted; any other long-term conditions resulting in a restriction.

Formal care
Includes all care services that are provided in the context of formal employment regulations (i.e. contracted services, by contracted paid care workers).

Informal assistance
Unpaid help or supervision that is provided to people with one or more disabilities or people aged 60 years and over living in households. It includes only assistance that is provided for one or more of the specified tasks comprising an activity because of a person’s disability or age. Informal assistance may be provided by partners, family, friends or neighbours.

Informal carer
A person providing care on a regular basis – often on an unpaid basis (e.g. partners, family, friends or neighbours).

Limitation
A person is defined as having a limitation if they have difficulty doing a particular activity, need assistance from another person, or use an aid.

Long-term health condition
A disease or disorder which has lasted or is likely to last for at least 6 months; or a disease, disorder or event (e.g. stroke, poisoning, accident etc.) which produces an impairment or restriction which has lasted or is likely to last for at least 6 months.

Mobility
Comprises the following tasks: getting into or out of a bed or chair; moving about the usual residence; going to or getting around a place away from the usual residence; walking 200 metres; walking up and down stairs without a handrail; bending and picking up an object from the floor; using public transport. The first three tasks contribute to the definitions of profound and severe core-activity limitation.

Palliative care
Care provided for people of all ages who have a life-limiting illness, with little or no prospect of cure and for whom the primary treatment goals is quality of life. It focuses on ‘living well’ until death.

Primary carer
A person who provides the most assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least 6 months and be provided for one or more of the core activities.

Respite care
Care given as an alternative care arrangement with the primary purpose of giving the carer or a care recipient a short-term break from their usual care arrangement.

Self-care
Comprises tasks including showering or bathing, dressing, eating, toileting, bladder or bowel control.

Young carer
A person under the age of 26 who provides care in a family affected by illness, disability, mental health and/or drug or alcohol issues.
Websites with further information on the topic
Aged Care Australia www.agedcareaustralia.gov.au
Australian Bureau of Statistics www.abs.gov.au
Better Health Channel www.betterhealth.vic.gov.au
CareSearch www.caresearch.com.au
Carers Australia www.carersaustralia.com.au
Carers ACT www.carersact.asn.au
Carers NSW www.carersnsw.asn.au
Carers Northern Territory www.nt.carersaustralia.com.au
Carers Queensland www.carersqld.asn.au
Carers South Australia www.carers-sa.asn.au
Carers Tasmania www.tas.carersaustralia.com.au
Carers Victoria www.carersvictoria.org.au
Carers Western Australia www.carerswa.asn.au
Department of Families, Housing, Community Services and Indigenous Affairs www.fahcsia.gov.au
Department of Health and Ageing www.health.gov.au
Department of Human Services www.humanservices.gov.au
Health Insite www.healthinsite.gov.au/topics/Carers
Working Carers Gateway www.workingcarers.org.au
Young Carers www.youngcarers.net.au

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# Index

**A**  
accommodation, supported 14  
aged care system 38-40  
A Stronger Fairer Australia 17, 18

**B**  
bereavement payment 14, 16, 19

**C**  
Carer Adjustment Payment 14, 16, 19, 20  
Carer Allowance 3, 8, 14, 16, 20, 28, 29  
Carer Payment 2, 3, 14, 28, 29  
**Carer Recognition Act 2010** 8, 15, 17, 18, 19  
carers  
  - age and gender 2, 41  
    - female 9-10  
    - male 11-12  
    - older parent 13  
    - young 8, 12, 16, 22  
  - benefits/rewards 5, 6  
  - challenges 5, 6  
  - cities 7, 8  
  - definition 1, 2, 3, 18, 21, 41  
  - disadvantage 6  
  - formal providers of assistance 26-27  
  - foster 2  
  - health and wellbeing 6, 7, 9-10, 13, 20, 29  
    - mental health problems 11, 28  
  - hours of care/week 2, 21, 30  
  - indigenous 7  
  - informal providers of assistance 26, 27  
  - kinship 2  
  - needs of 42-43  
  - non-primary 41  
  - numbers of 1, 2, 7, 12, 16, 21, 24-25  
  - paid (care workers) 2  
  - parents, and 2  
  - practical support 11-12  
  - primary 41  
  - projections 22, 23, 40  
  - reasons for becoming 1, 3  
  - recognition and respect 4, 19, 41  
  - rural and remote areas, in 7-8  
  - self-care 5-6, 26, 27  
  - services for 20  
  - socio-economic backgrounds of 2  
    - support 4, 29-30, 42-45  
  - **Carer Supplement** 14, 16, 19  
  - **Caring for older Australians**, report 20, 38-40  
  - case management/care coordination 43  
  - Centrelink 2, 3, 8, 28  
  - communication 26, 27

**D**  
dementia 11, 12  
depression 11, 28  
**Disability, Ageing and Carers, Australia** 24-25  
disability  
  - assistance, providers of 26-27  
  - care and support 20, 31-33, 37  
  - core-activity limitations 24, 25, 26, 27  
    - mild 24  
    - moderate 24  
    - profound 24  
    - severe 24  
  - health condition 24  
  - non-core activities 26-27  
  - physical conditions 25  
    - asthma-related disability 25  
    - back problems 25  
    - circulatory system, diseases of 25  
  - problems of present system 32  
  - prevalence 24-25  
  - divorce/separation 30

**E**  
economic value of informal care 21-23  
replacement value of care 2, 21  
education and training 20, 23, 43  
employment 21, 29  
  - flexible work arrangements 4, 16, 20  
  - opportunity costs 21  
  - paid 23, 29  
  - end-of-life care 46-48  
  - exhaustion 13

**F**  
family  
  - functioning 29-30  
  - support 43  
financial security/hardship 4, 6, 9-10, 19-20, 29

**I**  
income support 23  
information and access 19  
information resources 43  
institutionalised care 22  
  - interventions, multi-component 44

**M**  
mental health system 14, 15, 16  
mobility 26, 27  
multiple care responsibilities 30

**N**  
National Carer Recognition Framework 17, 18, 19  
National Carer Strategy 14-20  
  - funding 14-16  
  - priority areas 19-20  
National Disability Insurance Scheme (NDIS) 31-37  
National Disability Strategy 14, 15, 17  
National Injury Insurance Scheme (NIIS) 31-33, 36

**P**  
palliative care 46-48  
preventive health care 23  
Productivity Commission 20, 31-40

**R**  
relationships 6, 16, 29-30  
respite care 6, 8, 14, 20, 23, 43, 44  
rural/regional areas 7-8

**S**  
social inclusion 7, 17  
social isolation 6, 13  
stress 13

**U**  
unmet need for assistance 27

**W**  
**Women Carers in Financial Stress Report** 9-10