



**Australian Government**

# **National Carer Strategy**

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# Contents

<b>1. Foreword from Ministers</b>	<b>5</b>
<b>2. Summary</b>	<b>7</b>
<b>3. Carers in Australia</b>	<b>9</b>
<b>4. The Place of the National Carer Strategy</b>	<b>11</b>
SOCIAL INCLUSION STATEMENT	11
NATIONAL DISABILITY STRATEGY	12
THE NATIONAL CARER RECOGNITION FRAMEWORK	12
<b>5. Who is a Carer?</b>	<b>14</b>
<b>6. Roles and Responsibilities</b>	<b>15</b>
<b>7. The National Carer Strategy</b>	<b>16</b>
VISION	16
AIM	16
PRIORITY AREAS	16
PRIORITY 1: RECOGNITION AND RESPECT	17
PRIORITY 2: INFORMATION AND ACCESS	20
PRIORITY 3: ECONOMIC SECURITY	23
PRIORITY 4: SERVICES FOR CARERS	26
PRIORITY 5: EDUCATION AND TRAINING	30
PRIORITY 6: HEALTH AND WELLBEING	32

<b>8. Implementing the National Carer Strategy</b>	<b>34</b>
IMPLEMENTATION PLAN	34
ENGAGING CARERS, CARER REPRESENTATIVES AND OTHER STAKEHOLDERS	34
GOVERNANCE ARRANGEMENTS	35
MONITORING AND REPORTING	35
<hr/>	
<b>9. Summary Report of the National Carer Strategy Consultations 2010</b>	<b>36</b>
<hr/>	
<b>10. Endnotes</b>	<b>41</b>
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# 1

## Foreword from Ministers

Each morning in this country more than 2.6 million people wake up and their first thought is for the needs of someone else. These people are Australia's carers. They are family members, friends, partners, parents, children, or neighbours who care for a loved one with disability, medical condition, mental illness or who is frail aged.

Some carers shoulder their responsibilities alone; some share their responsibilities with others. Some do it full time, all day, every day, while others only occasionally. What they do not only makes a profound difference to the lives of those they care for, but makes an important contribution to the economic and social life of the nation.

Carers deserve the same opportunities as other Australians to participate in work and the community, and live a meaningful life. The Australian Government is determined to ensure Australia's carers get the support they deserve from the Government and the community. We have developed the National Carer Strategy to ensure that our community values and respects carers.

The National Carer Strategy represents the Australian Government's long term commitment to carers. It will guide future reforms, and it builds on reforms the Government is already delivering to better support carers. These include providing increased financial security through record increases to the Carer Payment; delivering carer recognition legislation; and establishing a National Disability Strategy.

The Government also knows that carers are concerned about adequate services for the people they care for. This is why we are doubling Commonwealth funding for more and better state and territory disability services through the National Disability Agreement, and making record new investments in mental health services. The Government's mental health reform package recognises the critical role of carers of people with mental illness, including through a major boost to mental health respite services.

The National Carer Strategy also includes some targeted new investments, such as a campaign to raise public awareness of the role and contribution of carers and to encourage people who don't formally recognise themselves as carers to become more aware of available services and supports to assist them.

The Government has also asked the Productivity Commission to conduct a landmark inquiry into a long-term care and support scheme for people with disability, including considering a national disability insurance scheme. This inquiry is an important complement to the National Carer Strategy, and the Government will consider the Productivity Commission's recommendations seriously.

We would like to acknowledge the many carers and organisations who attended workshops and focus groups, and who took the time to write submissions during the consultation process to develop the National Carer Strategy. We also thank Carers Australia and Children with Disability Australia for hosting workshops and conducting surveys with carers. These efforts were invaluable in helping us to develop the National Carer Strategy.

Carers make an enormous contribution to our nation. Their work, while often unseen and unacknowledged, is a critical part of the fabric of the Australian community. We are pleased to deliver the National Carer Strategy to support Australia's carers.



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The Hon Jenny Macklin MP  
Minister for Families,  
Housing, Community Services  
and Indigenous Affairs



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The Hon Nicola Roxon MP  
Minister for Health and Ageing



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Senator the Hon Jan McLucas  
Parliamentary Secretary for  
Disabilities and Carers



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The Hon Mark Butler MP  
Minister for Mental Health and Ageing

# 2

## Summary



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 ten 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 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
- \$42.6 million over four 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 four 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 four years to ensure fairer access to the Carer Supplement
- \$2.1 million over four years to ensure fairer access to Bereavement Payment
- \$1.6 million over two 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.

# 3

## Carers in Australia



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 socio economic 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 sixty 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.<sup>1</sup>

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.”<sup>2</sup>

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.

# 4

## The Place of the National Carer Strategy

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.

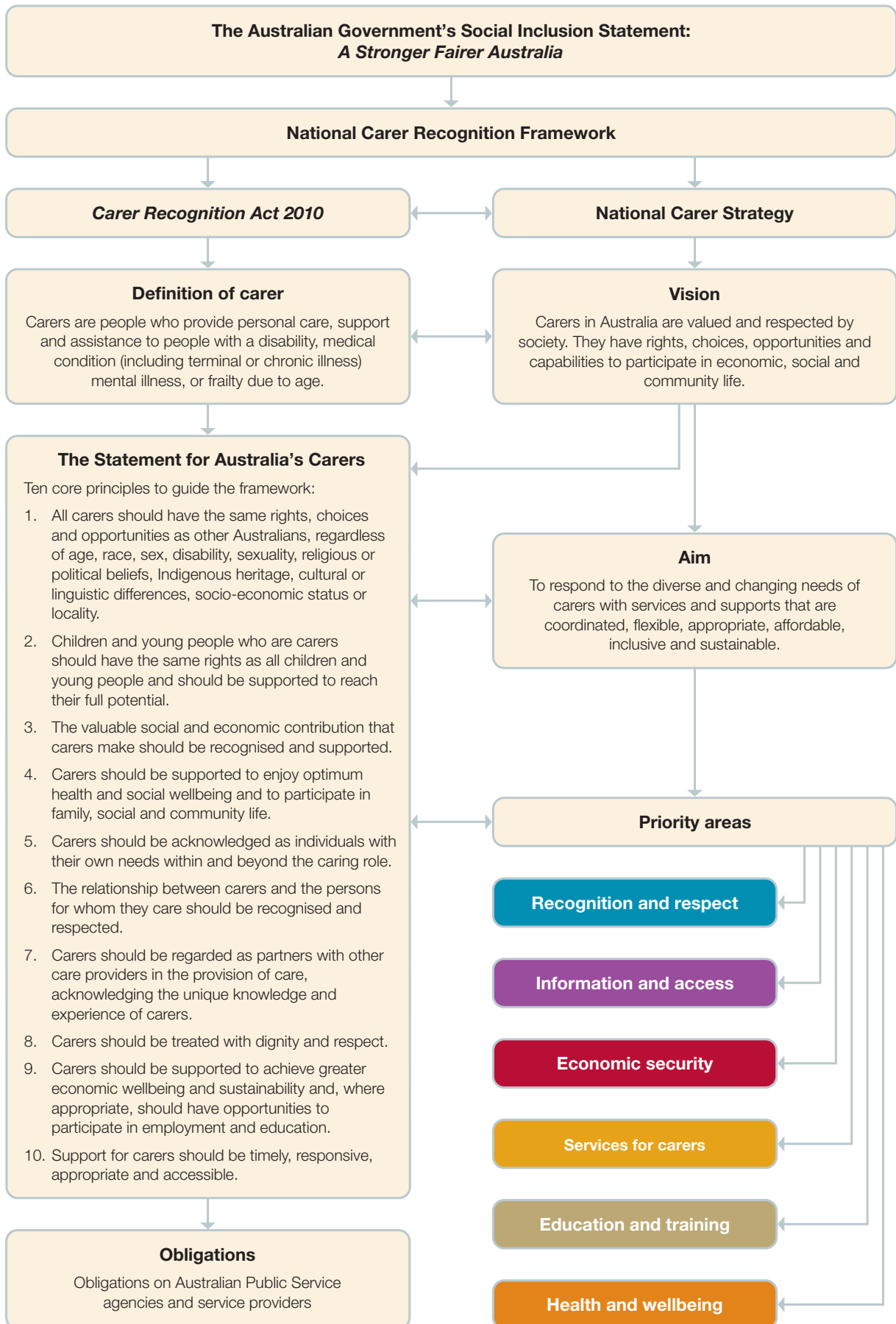
The purpose of the National Disability Strategy is to guide the development of policies, programs and services to better meet the needs of people with disability, their families and carers. The National Disability Strategy outlines the steps that will need to be taken to ensure its vision of an inclusive 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.

*Who Cares...? Report on the inquiry into better support for carers* was released in April 2009. The Australian Government responded in October 2009 by committing to the development of a National Carer Recognition Framework. The Framework consists of the *Carer Recognition Act 2010* and the National Carer Strategy.

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.



# 5

## Who is a Carer?

The National Carer Strategy adopts the same definition of carer as contained in the *Carer Recognition Act 2010*. Carers are defined as people who provide personal care, support and assistance to people with disability, medical condition (including terminal or chronic illness), mental illness, or frailty due to age.

Carers include family members, friends, relatives, siblings or neighbours. Grandparents or foster carers providing care to a child with disability, medical condition (including terminal or chronic illness) or mental illness are included as carers.

All of these people are defined as carers regardless of the amount of care, support and assistance they provide.

Carers not covered by the National Carer Strategy include people who are paid to undertake a caring role, such as formal care workers engaged under a contract of service. Other carers not included are those who provide voluntary care work for a charity or community organisation and those who provide care as a requirement of a course for their education and training.

# 6

## Roles and Responsibilities



The National Carer Strategy does not change the roles and responsibilities of the Australian Government or state and territory governments across the range of policies and programs that have an impact on carers and the people they care for.

The National Carer Strategy outlines the policy directions and actions the Australian Government will commit to developing and delivering. While the National Carer Strategy is the responsibility of the Australian Government, all state and territory governments have committed to identifying strategies and activities that complement the National Carer Strategy, or identify areas that can be worked on cooperatively.

# 7

## The National Carer Strategy

### 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.

Our vision is of an Australian community where governments, business, health and community professionals, as well as the wider community, value and respect the contribution that carers make to Australian society and work together to provide them with choices and opportunities to participate in economic, social and community life.

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

The aim sets out how the vision will be achieved. It will guide the development of work undertaken in each of the priority areas.

Six priority areas of equal importance.

The National Carer Strategy's six priority areas contain long-term policy directions, as well as areas for action in the short term.

## **PRIORITY 1: Recognition and respect**

Carers are recognised, valued, respected and have their rights protected.

There are many reasons why carers provide the care they do. Most carers provide care out of love and believing they can provide a better quality of life for their family member or friend than anyone else. In many cases carers provide care because the demand for formal care services far exceeds supply and there is no alternative.

“ I look after my husband to the best of my ability, allowing him to be happy and feel loved in familiar surroundings.”<sup>3</sup>

Despite their extraordinary devotion and effort, many carers feel they are invisible and are not valued or respected for the invaluable work they do. They feel taken for granted – not by the people they care for, but by the rest of the community.

“ Carers want and need more than just ‘recognition’. They want understanding and appreciation of the complexity of their role, their varying situations and needs, and acknowledgement of their right to continue to participate in all aspects of community life.”<sup>4</sup>

Many carers express dissatisfaction in their dealings with health and community professionals and feel that they are not acknowledged or respected as experts in providing care. Often they feel ignored or dismissed, despite the valuable insight, expertise and information they can provide.

“ We are frustrated by the fact that the carer of the patient is not recognised by the professional care providers. This is frustrating because we feel that we are out of the loop.”<sup>5</sup>

### **POLICY DIRECTION 1**

#### **Strengthen awareness and understanding of the valuable role of carers and their rights as individuals**

Everyone in the community needs to be aware of and understand the invaluable contribution of carers. Carers also need to be acknowledged as individuals, with their own rights and needs beyond their caring role. Promoting an awareness and understanding of the rights and needs of carers is important so that they have every opportunity to participate in economic, social and community life.

This includes people who provide care and support but who don't formally identify as carers. However they choose to define and see themselves, they do need to be aware of the support and services available to assist them.

Most importantly, those who develop and implement policies, programs and services for carers and the people they care for must be aware of and consider the needs of carers.

## What the Australian Government is doing now

- The *Carer Recognition Act 2010* commenced on 18 November 2010. It acknowledges the vital social and economic contribution that carers make to society. The Act includes “The Statement for Australia’s Carers” which sets out ten principles that Australian Public Service (APS) agencies and funded service providers must consider when developing policies and delivering services for carers and the people they care for.
- Guidelines for the implementation of the *Carer Recognition Act 2010* give practical assistance to APS agencies and funded service providers on how they can be more responsive to the needs of carers.

## What the Australian Government will do next

- 1.1 Provide \$1.6 million over two years to fund a national campaign to raise public awareness of the role of carers and encourage people with caring responsibilities to seek assistance and support.

The campaign will promote services and supports available for carers. It will target the community as a whole as well as highlighting the needs of particular groups such as older carers, young carers, Indigenous carers, carers in rural, regional and remote areas and carers from culturally and linguistically diverse backgrounds.

- 1.2 Work with peak bodies, community care, mental health services and allied health professionals to help them identify and support people who do not identify themselves as carers.

- 1.3 Promote the principles of the *Carer Recognition Act 2010* to APS agencies and funded service providers.

This will include consulting with carers and representative organisations in the development, implementation and evaluation of policies, programs and services that directly affect carers and the people they care for.

- 1.4 Identify key legislation and policy for review to improve the recognition of carers.

## **POLICY DIRECTION 2**

### **Ensure that carers are engaged as partners in care**

Health and community care professionals should involve carers as partners in the provision of formal care. In everything from planning to service delivery, carers should be involved where appropriate.

Involving carers as partners in care can have positive results for all. Health and community care professionals will be able to better plan and respond to the needs of individuals because of the experiences and insight provided by carers. The person who is ill, aged or has disability will benefit from having a strong, trusting and well informed care team.

Health and community care professionals, education and training providers, business and community members therefore need greater awareness and understanding of the critical role that carers play.

### **What the Australian Government is doing now**

- The Australian Government's *Charter of Rights and Responsibilities for Community Care* recognises that services need to be delivered in a way that respects people who need care, their families and carers.

The Charter provides for carers to:

- be recognised as partners in care
- participate in decisions relating to care situations where the person being cared for does not have sufficient capacity.

### **What the Australian Government will do next**

- 1.5 Promote the importance and value of involving carers as partners in care to health and community care professionals.
- 1.6 Promote service models that effectively involve carers as partners in the provision of care.
- 1.7 Increase awareness and acknowledge the role, skill and experience of carers in reforms to health, disability, aged care, mental health, and education and training systems.

## PRIORITY 2: Information and access

Carers have access to appropriate and timely information which makes it easier for them to get support.

Services and supports for carers and the people they care for are fragmented across a number of different service delivery systems. Carers find it difficult to navigate the different systems to locate services relevant to their needs and determine what help and supports are available.

“ Although services are available to carers, trying to access those services is akin to being in an ever-increasing maze with illegible signposts so that the carer never really knows where to go or which direction to take.”<sup>6</sup>

Carers in regional and remote locations or from culturally and linguistically diverse backgrounds face particular difficulties.

“ The system is a nightmare. It is so complex for people who have good English comprehension. A migrant or a refugee recently arrived would not know how to navigate the system or what to ask for.”<sup>7</sup>

Carers often express the need for a centralised source of information about their role as well as the various services and supports that are available to them.

“ There needs to be a one stop shop where clients can get accurate information about the resources they are entitled to. At the moment it takes several years to get a basic understanding of the resources available.”<sup>8</sup>

### POLICY DIRECTION 1

#### **Provide access to up-to-date and relevant information so carers can make informed decisions**

Carers must be able to obtain relevant and reliable information quickly and easily. Front line agencies, whether in the health, disability, aged or community sectors need to be better informed so they can point carers in the right direction quickly.

Information services need to be highly visible and responsive to changing needs.

## What the Australian Government is doing now

- A new “front end” for aged care services is being developed. This will assist older Australians, carers and their families to more easily access information about aged care services. There will be a phased implementation process commencing in July 2011 to ensure Australia gets the best system that meets the needs of clients, carers and service providers.
- Commonwealth Carelink and Respite Centres provide information about a wide range of community, aged care and support services.  
Centres can also help carers with options on how to take a break through short-term and emergency respite services.
- The Young Carers Respite and Information Services Program provides information to young carers to support them in managing the challenges they face as part of their caring role.

## What the Australian Government will do next

- 2.1 Progress the implementation of a new “front end” for aged care services that will improve information, intake and assessment.
- 2.2 Address the information needs of carers who need particular support such as older carers, young carers, Indigenous carers, carers from culturally and linguistically diverse backgrounds, and carers living in regional, rural and remote areas.
- 2.3 Educate agencies that are the first point of contact for carers—such as health, community, and school-based professionals—about how to quickly link carers with appropriate and relevant information.

## POLICY DIRECTION 2

### Improve access to existing services and supports

Carers need improved access to services and supports, both for the people they care for and for themselves. This means fully informing and supporting carers to navigate the system and helping them to gain access to existing services and supports where they live.

Many carers face challenges with gaining access to services and supports across different service systems such as a person caring for a child with disability as well as a frail aged parent.

Current and future reforms to the aged care, disability, mental health, health and community care systems should deliver improved access to services and supports by creating better links across these systems.

## What the Australian Government is doing now

- Working in partnership with state and territory governments to simplify access to services and supports for people with disability, carers and their families provided under the National Disability Agreement.
- The Productivity Commission is conducting an inquiry into a long-term care and support scheme for people with disability. This inquiry is examining alternative approaches to the funding and delivery of disability services.

## What the Australian Government will do next

**2.4** Progress the implementation of the new “front end” for aged care that will help older Australians, carers and their families to access aged care services.

**2.5** Provide \$549.8 million (including \$343.8 million over five years in new expenditure) to provide coordinated care and flexible funding for people with severe mental illness and complex multi-agency care needs and their families.

This will provide care facilitators for around 24,000 people with severe and persistent mental illness and their families to ensure all of the person’s care needs, clinical and non clinical, are being addressed.

## **PRIORITY 3: Economic security**

Carers have economic security and opportunities to participate in paid work.

Many carers would like to engage in paid work, or return to paid work, but cannot because of the difficulty in balancing employment with their additional responsibilities.

“ Each day is a constant struggle as my husband and I try to combine our full time careers with our daughter’s needs. ”<sup>9</sup>

Others can not work due to their significant commitments.

“ My time is fully occupied with either one or both of my children needing help – this restricts my getting a job. ”<sup>10</sup>

Many carers are reliant on the income support system because the demands of their caring role do not enable them to participate or fully engage in paid work. This affects not only their current circumstances but has a significant impact on their future, restricting their ability to save for retirement.

“ Primary carers are likely to be in the poorest two-fifths of all households and 55 per cent receive a government pension as their main source of cash income. ”<sup>11</sup>

### **POLICY DIRECTION 1**

#### **Improve supports so carers have more options to participate in paid work**

Having the opportunity to participate in paid work while caring for someone else is more than a matter of finance - it also has a dramatic impact on the social and emotional wellbeing of everyone in the family.

There are many reasons why carers find it difficult to balance paid work and their additional responsibilities. Inadequate or expensive alternative care options, inflexible employment conditions, and lack of employer support are all reasons why carers find it difficult to balance a paid job with informal care.

At the end of caring many people also find it difficult to return to work after years out of the workforce.

#### **What the Australian Government is doing now**

- Job Services Australia provides support for carers who wish to enter or re-enter the paid workforce and for people returning to the workforce after their caring role ends. It provides opportunities for training, skills development and work experience and provides tailored assistance to ensure responsiveness to individual circumstances.

- The *Fair Work Act 2009* provides the right to request flexible working arrangements to eligible working parents of children under school age, and parents of children under 18 years with disability.  
Carers of children under the age of 18 years with disability also have the right to request flexible working arrangements.
- Under the *Fair Work Act 2009*, measures such as Individual Flexibility Arrangements support employees with caring responsibilities. They allow for variations to modern awards or enterprise agreements so that employers and employees can make arrangements that suit their particular needs.
- The Pension Education Supplement can assist eligible carers who receive income support payments with the costs of study allowing participants to obtain qualifications to make them more competitive in the labour market.
- Over the next four years \$26.2 million is being provided to the Outside School Hours Care for Teenagers with Disability Program. This program supports parents and carers of children with disability aged 12–18 years to join or return to paid work.

## What the Australian Government will do next

### 3.1 Provide \$2.9 million over four years for fairer access to Carer Supplement.

This will allow access to the Carer Supplement for those carers who fail to qualify as they or their partner worked in the fortnight of July 1 in any given year. This will help ensure the income support system does not act as a disincentive to carers working in paid employment at this time of year.

### 3.2 Increase opportunities for carers who are seeking support to remain in the workforce, re-enter the workforce, or increase their participation in the workforce by extending the demonstration Day Respite Pilot, which was due to cease on 30 June 2011, for a further twelve months to allow time to evaluate the effectiveness of long day respite options for employed carers.

### 3.3 Consult with stakeholders on expanding the right to request flexible working arrangements under the *Fair Work Act 2009*.

This will include consideration of expanding the right to request flexible working arrangements to employees caring for older Australians and those caring for a person with a serious long-term illness or disability.

### 3.4 Address barriers and disincentives for carers to volunteer into employment services.

## **POLICY DIRECTION 2**

### **Ensure the income support system continues to provide adequate support**

Carers who provide daily care and support to a person who has disability, mental illness, severe medical condition or who is frail aged need financial assistance.

The income support system is an important safety net that ensures on-going financial support for carers who cannot work because of their substantial caring responsibilities.

It is therefore important to consider the specific needs of carers in future reforms to the income support system.

### **What the Australian Government is doing now**

- Around \$5 billion per annum<sup>12</sup> is provided to carers through the following payments and supplements: Carer Payment, Carer Allowance, Carer Supplement, Child Disability Assistance Payment, and the Carer Adjustment Payment.
- Major reforms have been made to the income support system including:
  - significant pension increases to carers receiving Carer Payment
  - the introduction of a permanent annual Carer Supplement of \$600
  - new and more generous indexation arrangements.

Since these reforms began, Carer Payment has increased by \$128 a fortnight for singles on the maximum rate and \$116 a fortnight for couples combined on the maximum rate.

### **What the Australian Government will do next**

- 3.5** Provide \$42.6 million over four years to extend automatic eligibility for Carer Allowance (child) for carers of children with Type 1 Diabetes aged between 10 and 16 years.

This will assist an additional 2,200 carers per year who are currently not in receipt of Carer Allowance (child) for their child aged between 10 and 16 years with Type 1 Diabetes.

- 3.6** Provide \$10.3 million over four years to continue the Carer Adjustment Payment from 1 July 2012.

This is 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.

- 3.7** Provide \$2.1 million over four years for fairer access to Bereavement Payment.

This will allow access to Bereavement Payment for people receiving Carer Allowance (adult) and an income support payment (other than Carer Payment) who do not currently receive a Bereavement Payment on the death of the person they have been caring for. This will provide some assistance at a difficult time.

## **PRIORITY 4: Services for carers**

Carers are supported with appropriate, timely and accessible services.

Carers often feel stressed, vulnerable and alone. Many only turn to the formal service system when they have reached breaking point.

“Many carers do not want to give up their caring role, rather they want to continue to provide care with adequate support.”<sup>13</sup>

Carers require services that are accessible, affordable, flexible and responsive to their individual needs and those of the people they care for. This is particularly important when circumstances change.

“This transitional period is confrontational. It is not easy for me due to lack of knowledge of choices available.”<sup>14</sup>

Carers also want to have more control and flexibility over the use of available funding. They want to make sure they are able to use the money in a way that best suits them, the person they are caring for, and their family.

“The most effective way to support families is to have a well resourced and effective system that is based on the principles of individualised funding and person centred planning.”<sup>15</sup>

### **POLICY DIRECTION 1**

#### **Support services for carers respond to individual circumstances**

Carers need access to appropriate, affordable and timely supports and services for themselves and the people they care for. Often support services needed by the carer and the people they care for are linked. This means it is important for support to be based around the care relationship.

Carers want services and supports to be flexible and respond to their changing circumstances. This includes when they start caring, when they temporarily move out of caring and when their role ends.

## What the Australian Government is doing now

- The Productivity Commission is conducting an inquiry into long-term care and support for people with disability, including consideration of a national disability insurance scheme.  
Providing adequate, timely and effective support to people with disability will also improve the lives of their families and carers.
- The Productivity Commission has undertaken an inquiry into the aged care system to ensure it can meet future challenges. Reform in this area will also have a significant impact on those caring for older Australians.
- Over the next four years \$54.2 billion is being provided for aged care, including \$989 million to improve respite and information services to carers of people who are frail aged.
- The Supported Accommodation Innovation Fund has been established to build innovative, community-based supported accommodation places for people with disability. This \$60 million program is intended to help address the shortage of supported accommodation and respite for people with disability.  
Supported accommodation and respite places will be targeted towards adults with severe or profound disability in need of supported accommodation or respite who may be on waiting lists and who may have ageing carers.
- Over the next two years \$197 million is being provided to the Mental Health Respite initiative. This will provide a range of flexible respite and support options for carers of people with severe mental illness as well as carers of people with intellectual disability.
- The \$220 million Helping Children with Autism package delivers education and support for children with Autism, their families and carers. The package funds specialist advisers, early intervention services, specialist play groups, Autism Specific Early Learning and Care Centres, family workshops and an Autism Spectrum Disorder website.
- Children diagnosed with moderate or greater sight or hearing impairments, cerebral palsy, and Down Syndrome or Fragile X syndrome will be able to access early intervention/treatment services through the \$146.5 million Better Start for Children with Disability initiative.  
This will help reduce the financial burden on parents and carers of children with disability and make vital early intervention services more affordable and accessible.
- The Veterans' Home Care program provides low level care to veterans and war widows/widowers to enable them to remain in their homes, including in home respite, emergency short term home relief, and approval for residential respite.
- From 1 January 2009 to 30 June 2015, \$7.6 billion is being provided to state and territory governments to increase and improve specialist disability services provided under the National Disability Agreement.

## What the Australian Government will do next

- 4.1 Provide \$61 million over five years to double the number of Family Mental Health Support Services. The new services will support more than 32,000 children and young people with, or at risk of developing, a mental illness. Services will include counselling, support to attend school and to improve relationships with family and friends.
- 4.2 Provide \$54.3 million over five years to expand mental health respite services. This will give up to 1,100 carers and families of people with a mental illness greater access to flexible respite support services.
- 4.3 Improve carer support programs to promote access to timely and appropriate respite arrangements.
- 4.4 Test and support different models of consumer-directed carer support to provide more control and flexibility over the use of available funding.
- 4.5 Ensure consideration of the needs of carers in the development and introduction of the new “front end” to aged care.

## POLICY DIRECTION 2

### Improve data to inform future policy, program and service delivery

Reliable and comprehensive data about carers is essential to developing policies, programs and services that are responsive to their needs.

It can be difficult however to obtain good quality information because people may not always formally identify as carers, may care for more than one person, or share care with other carers. It is difficult to easily capture the diversity of care provided in the community and document all of the unique relationships and circumstances carers find themselves in.

It is therefore important to collect as much information as possible to ensure policies and programs are responsive to everyone’s individual needs.

### What the Australian Government is doing now

- Australia’s main statistical source of data on carers is the Australian Bureau of Statistics’ Survey of Disability, Ageing and Carers (SDAC).  
SDAC captures information about the number and characteristics of carers and the nature of care relationships. For primary carers, it shows the supports that are required and available, and measures the impact of the caring role on their lives.
- A National Need and Supply Model has been developed that can measure the need, including unmet need, for specialist disability services. This information will help in planning support services for people with disability, their families and carers.

## What the Australian Government will do next

- 4.6 Work with the Australian Bureau of Statistics, state and territory governments and other research institutions to improve information, data and research about carers.
- 4.7 Work with state and territory governments to develop more robust national indicators for the measurement of outcomes for carers.
- 4.8 Continue to develop performance benchmarks, national quality assurance systems, and holistic and person-centred care in the aged care system.

## PRIORITY 5: Education and training

Carers have the skills to undertake their role and opportunities to participate in formal education and training.

Carers often begin their caring role with little or no warning.

“Carers can come into their caring responsibilities at any stage throughout their life. This could be with the birth of a child with a disability, an accident, the onset of mental illness, the diagnosis of a terminal illness or with an ageing parent becoming frail.”<sup>16</sup>

Caring responsibilities can affect the ability of carers to participate in education and training opportunities. Many carers find it difficult to balance their additional responsibilities with the need to meet deadlines and attendance requirements.

“The need for flexibility is also important in relation to education and training. Carers may benefit from the flexibility to complete education at home, having their caring skills recognised as part of their education, taking periodic leave from study commitments, and having extended timeframes for completing courses.”<sup>17</sup>

Young carers in particular experience difficulties completing their education and participating fully in school life. They want schools, teachers and education systems to be more understanding and supportive of the additional demands on their time and resources.

“Only four per cent of primary young carers between the ages of 15 to 25 years remain in education compared to 23 per cent of young people in the same age group.”<sup>18</sup>

### POLICY DIRECTION 1

#### Carers have the skills and knowledge to undertake the caring role

Carers need to develop a range of skills in order to effectively carry out their important role.

They need practical skills such as administering medications and safe manual handling techniques. They also need to acquire an array of advocacy skills in order to effectively negotiate with clinicians, service providers and support workers.

#### What the Australian Government is doing now

- As part of the Helping Children with Autism package, Autism Associations in each state and territory provide workshops for families and carers of children with Autism Spectrum Disorder. The workshops provide support for parents who are in the “early days” of their journey through the assessment and diagnostic process.
- The Community Services Training Package offers qualifications that formally recognise current skills or help carers to develop the skills they need for their caring role.

## What the Australian Government will do next

- 5.1 Examine and identify gaps in programs and services that support carers to gain the skills they need to commence, maintain and cease their caring role.
- 5.2 Work with the Community Services and Health Industry Skills Council to identify ways to address the skills development needs of carers.

## POLICY DIRECTION 2

### Carers are supported to undertake education and training opportunities

For carers to make the most of the study and training opportunities available they need accessible and appropriate support services.

Young carers need support to ensure they are able to complete their education and participate fully in school life. It is important that schools, teachers and the education system are more understanding of the impact of caring. Supports and services for young carers need to be tailored and flexible and responsive to individual needs.

## What the Australian Government is doing now

- The Young Carers Respite and Information Services Program assists young carers who need support to complete their secondary education or vocational equivalent due to the demands of their caring role. The program enables school aged carers to access flexible respite and age appropriate support services.
- The Youth Connections Program provides individual and flexible case management to young people, including young carers, who are at risk of leaving, or who have already left, school.

## What the Australian Government will do next

- 5.3 Explore ways to meet the needs of people with caring responsibilities who do not formally identify as carers and develop greater flexibility in educational settings.
- 5.4 Consider the needs of carers in reforms to education, training and skills development initiatives.
- 5.5 Improve awareness and understanding among education and training providers of the impact of caring responsibilities on students.

## PRIORITY 6: Health and wellbeing

The health and wellbeing of carers and their capacity to participate in social and community life is improved.

Providing care has a significant impact on physical, emotional and mental health. A lack of support services for the person they care for as well as themselves means carers often carry out their role in very difficult circumstances, compounding the impact.

“ One-third of all carers report they feel weary or lacking in energy because of the care provided, 29 per cent report that they feel worried or depressed and 29 per cent report that their wellbeing has changed as a result of caring. ”<sup>19</sup>

Carers report high rates of emotional stress and many feel isolated and alone.

“ I can and do function as best as I can – and really try to stay positive and energetic for my kids. ”<sup>20</sup>

The additional demands on carers often leaves them with little time or energy to pursue community activities or even regular contact with other family and friends.

“ Provide specific opportunities for carers to have fun, to socialise and relax. ”<sup>21</sup>

### POLICY DIRECTION 1

#### Improve supports for the physical and emotional health and wellbeing of carers

Carers need information and support to ensure they develop strategies to manage their own physical and emotional health. They need to learn how to cope and manage stress.

It is important to ensure general practitioners and front-line health staff learn to recognise when carers are suffering from poor physical and emotional health and can help them to locate and obtain support.

#### What the Australian Government is doing now

- Under the National Health Reforms, Medicare Locals have been established to work with primary health care providers, hospital networks and local communities to improve the planning and coordination of services.
- The National Carer Counselling Program provides counselling and related emotional and psychological support services to carers.
- Improving family relationship and support services that cater specifically to the needs of parents, siblings and carers through reforms to the Family Relationship Services for Carers program.

## What the Australian Government will do next

- 6.1 Increase awareness among general practitioners and other front line staff of the physical and emotional health issues that carers may experience.
- 6.2 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.
- 6.3 Increase its share of public hospital funding to 45 per cent of all efficient growth in public hospital services from 2014–15 and to 50 per cent from 2017–18.

## POLICY DIRECTION 2

### Give carers greater opportunities to participate in family, social and community life

Carers and families need adequate and timely breaks from their additional responsibilities to attend to their own needs and to participate in family, social and community life.

But in order to have a break, carers need access to flexible, reliable and responsive respite and support services.

Caring can also lead to the loss of social networks and social isolation. It is important for everyone to provide opportunities and supports for carers to participate in family, community and social life.

## What the Australian Government is doing now

- Providing support to parents and carers of young children with disability or chronic medical conditions through the MyTime Peer Support Program.  
A \$10.5 million investment over three years to 2013 will support 262 MyTime groups across the country. The groups give parents and carers the opportunity to meet with others in similar circumstances, socialise and share information.
- The National Strategy for Young Australians aims to improve the health and wellbeing of young people. Young carers, siblings and those who are the children of carers are given priority in the Strategy.

## What the Australian Government will do next

- 6.4 Amend the scope of respite programs to be more creative and responsive to what carers and people being cared for want and need, including opportunities for carers to participate in social and community life.
- 6.5 Fund a young carer festival in each state and territory to give young carers an opportunity to have a break from their caring responsibilities and to relax, socialise and have fun with their peers.
- 6.6 Make locally-based peer support groups a priority within existing community grants programs.

# 8

## Implementing the National Carer Strategy

### Implementation plan

The National Carer Strategy provides a framework for ensuring Australia's carers have the support they need to balance their caring responsibilities with participation in economic, social and community life.

More work needs to be done to put the National Carer Strategy's principles and ideas into action. In the first year of operation, the Australian Government will commence the roll-out of the National Carer Strategy's \$60 million and develop an implementation plan. It will also identify how success will be measured.

The National Carer Strategy will be reviewed at key points – particularly when major reforms are considered or introduced. The outcomes from the Productivity Commission inquiries into disability care and support and aged care will have an impact on the further development and implementation of the National Carer Strategy.

### Engaging carers, carer representatives and other stakeholders

The Australian Government will continue to work collaboratively with carers, their representative organisations, the National People with Disability and Carers Council, and state and territory governments to implement the National Carer Strategy.

## **Governance arrangements**

The Commonwealth Carers Forum, which includes Australian Government agencies that have responsibility for supporting carers, will be responsible within the Government for implementing the National Carer Strategy. This will include monitoring and reporting on progress in each of the priority areas.

## **Monitoring and reporting**

Monitoring progress is essential to ensure the National Carer Strategy is meeting its goals and delivering better outcomes for Australia's carers.

The Carers Forum will monitor and report annually on progress in the six priority areas to the Council of Australian Governments' Standing Councils of Community Housing, Disability and Community Services; and Health.

# 9

## Summary Report of the National Carer Strategy Consultations 2010

### Introduction

This summary report is based on the nationwide consultations conducted in November and December 2010 by the Australian Government, Carers Australia, and Children with Disability Australia to inform the development of the National Carer Strategy. It also includes material obtained from written submissions which were accepted until the end of January 2011.

Common themes or significant issues raised in consultations are outlined. Given the diversity of the workshops and the large number of submissions received, it was not possible to itemise and include all of the detailed information provided throughout the consultation process.

### Consultation process

During Carers Week 2010, the Australian Government launched a discussion paper *Towards a National Carer Strategy: A discussion paper from the Australian Government* to inform the development of the National Carer Strategy.

Nationwide feedback was sought from carers, peak organisations, advocates and service providers on the vision, aim and goals set out in the discussion paper.

Between 1 November 2010 and 1 December 2010 a series of consultation workshops were held. These sessions were well attended and included individual carers as well as peak organisations, advocates and service providers.

Twenty workshops were held in all capital cities and in select regional locations including Alice Springs, Cairns, Murray Bridge, Port Macquarie, Roma, Ulladulla, and Launceston. A total of 377 representatives and organisations attended.

During the same period, Carers Australia consulted with carers and invited written submissions from individual carers. Children with Disability Australia also surveyed and conducted consultations with parents and carers of children with disability. Both organisations submitted reports summarising the outcomes of their work. The public was also invited to express their views through written submissions. Around 300 submissions were received from individual carers, peak organisations, advocates and service providers from all over Australia. Those received by the end of January 2011 were incorporated in the analysis.

## Overview of feedback

Overall there was strong support for the proposed National Carer Strategy. This was reflected not only in the large number of people attending the workshops and making written submissions but also in the positive comments made by participants.<sup>i</sup> All participants stressed the importance of developing a National Carer Strategy that would make a tangible difference to the lives of carers and were pleased to have the opportunity to share their thoughts about how to achieve that goal.

Many participants stressed the importance of including a preamble, or opening statement, which would:

- define the term ‘carer’ and distinguish between a paid, formal care worker and an unpaid, informal carer<sup>ii</sup>
- outline the principles in the *Carer Recognition Act 2010* (Cth.)<sup>iii</sup>
- profile carers in Australia, including the disadvantages they face and the value of their economic and social contribution
- explain how the National Carer Strategy fits in with other government reform agendas.<sup>iv</sup>

## Vision

There was widespread support for the vision and aim outlined in the discussion paper. Consultation participants stressed that the development of the National Carer Strategy should begin with a vision of an Australian community where carers had the same rights, choices and opportunities as all other Australians.

<sup>i</sup> Collated input from individual carers, key peak organisations, advocates and service providers via consultation workshops and written submissions to government; and Carers Australia and CDA consultation summary reports.

<sup>ii</sup> Consultation workshops in Adelaide, Melbourne and Perth.

<sup>iii</sup> Consultation workshop in Canberra.

<sup>iv</sup> Consultation workshops in Adelaide, Port Macquarie and Sydney.

## Aim

There was extensive support for the aim to be broadened to promote recognition that all Australians—governments, business, communities and individuals—have a role to play in improving the lives of carers and those they care for.

## Goals

There was strong support from participants for the five goals outlined in the discussion paper. While most agreed with the general directions, some suggested additions and offered alternative terminology. In particular a number suggested that Goal 3 be split into two goals - one addressing the information needs of carers, and the other addressing services for carers.

Feedback on each of the goals is outlined below.

### Goal 1: Better recognition for carers

Generally all participants supported the first goal. Most were positive about the implementation of the *Carer Recognition Act 2010*.

Participants also suggested a number of issues needed further consideration. These included:

- the need to raise community awareness of carers and their role
- the need to raise awareness of the caring role among people who do not formally recognise themselves as carers
- the need to develop a national community awareness campaign to promote recognition of carers, the diversity of caring relationships and care situations, and to identify 'hidden' carers
- the importance of valuing carers for their economic and social contribution and promoting greater respect
- the importance of acknowledging and respecting carers as partners in the provision of care. Participants were keen to ensure health, community care professionals and service providers actively consult carers on matters such as planning.

### Goal 2: Better support to help carers work

Most participants suggested broadening the second goal to include the need for improved economic security, rather than simply focus on participation in paid work.

Participants raised a number of issues to be considered including:

- the importance of recognising the difference between 'work' and 'paid employment'—particularly as many people experience caring as a full-time job<sup>v</sup>
- the importance of ensuring carers have greater choice about when to engage in paid work, when to care and when to do both

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<sup>v</sup> Consultation workshops in Adelaide, Brisbane, Darwin and Melbourne.

- greater recognition that some carers do not have the capacity to undertake paid work, particularly where caring responsibilities are significant<sup>vi</sup>
- the need to provide flexible respite options so carers have improved employment choices
- the importance of allowing carers to have access to leave and flexible working conditions to help them combine work and caring responsibilities. Participants argued this should include considering more flexible provisions for carers in the *Fair Work Act 2009*
- the need to provide carers with education and training to help with the transition back into paid employment after a period of caring
- ensuring the income support system is flexible and equitable, particularly with regard to eligibility
- the need to increase income support payments for carers to provide financial security for those unable to engage in paid employment.

### Goal 3: Better information and support for carers

Many participants suggested Goal 3 should be split in two - one goal focused on information and the other focused on improving services. Most emphasised the importance of improved service coordination.

Key issues that emerged during the consultations included:

- the need to provide carers with information that is simple, consistent and available in various formats and languages
- the importance of developing a centralised source of information to help carers in their role, including information on the various services and supports that are available
- ensuring health and community service staff and workers were more familiar with available services and supports to help carers locate and access support
- ensuring respite is flexible and responsive to individual need
- the importance of allowing carers greater control and flexibility in the use of consumer directed funding to allow them to make decisions about how to spend the available dollars to best suit the needs of the person they are caring for and their unique circumstances<sup>vii</sup>
- the need to eliminate duplication by coordinating and streamlining support for carers and the persons they care for across all levels of government
- improving the way personal information is shared between government agencies and programs so families do not have to continually repeat their stories, particularly families with stable, life-long conditions
- the need to improve data collection and research to inform the development of evidence-based policy and programs for carers.

<sup>vi</sup> Written submission to government, CA and CDA consultations.

<sup>vii</sup> Consultation workshops in Adelaide, Brisbane, Darwin and Melbourne.

## Goal 4: Better education and training for carers

Most stakeholders generally agreed with the focus of Goal 4. Issues suggested for further consideration included:

- greater recognition that carers acquire unique skills and knowledge while performing their role
- the need to support carers to participate in education and training
- the importance of distinguishing between education and training for paid employment, and education and training required to undertake the caring role
- the need to equip carers with the skills they need - both practical skills for the tasks they need to perform and to ensure they are able to sustain their role. The kinds of skills required include:
  - practical tasks such as manual handling, administering medication, hygiene and infection control
  - administrative tasks such as financial literacy
  - assistance to re-engage with education, training and the broader community
  - coping and stress management skills
  - advocacy skills
- greater recognition that community-based carer groups, peer support groups, ex-carers and mentors are vital in supporting the need for improved coordination of local and regional training opportunities
- the need for better support for young carers to complete their education and to engage in secondary and tertiary education.

## Goal 5: Better health and wellbeing for carers

Most stakeholders generally agreed with the focus of Goal 5. A number of participants suggested that if the first four goals of the National Carer Strategy were met, then goal five would automatically be achieved. They suggested therefore broadening this goal to include a greater focus on social inclusion and participation in community life.

Participants stressed the importance of:

- providing flexible and accessible respite to ensure carer health and wellbeing
- providing carers with access to quality health care including mental health supports such as counselling
- educating general practitioners, health professionals and service providers about carer health and wellbeing, including potential health risks such as depression and mental illness.

Participants suggested a holistic approach to health and wellbeing of the whole family unit. They called for more supports and assistance to help carers participate in social activities and commented on the importance of these to maintaining health and wellbeing.

# 10

## Endnotes



- <sup>1</sup> Australian Bureau of Statistics, *4440.0—Survey of Disability, Ageing and Caring*, Commonwealth of Australia, 2009.
- <sup>2</sup> Name withheld, *Submission 121 from nationwide consultations for developing the National Carer Strategy* (unpublished), 2010.
- <sup>3</sup> Name withheld, Submission 61 to House of Representatives Standing Committee on Family, Community, Housing and Youth, *Inquiry into better support for carers*, 2009
- <sup>4</sup> Name withheld, *Submission 99 from nationwide consultations for developing the National Carer Strategy* (unpublished), 2010.
- <sup>5</sup> House of Representatives Standing Committee on Family, Community, Housing and Youth, 2009, p. 97.
- <sup>6</sup> House of Representatives Standing Committee on Family, Community, Housing and Youth, 2009, p. 158.
- <sup>7</sup> House of Representatives Standing Committee on Family, Community, Housing and Youth, 2009, p. 76.
- <sup>8</sup> Name withheld, *Submission 21 from nationwide consultations for developing the National Carer Strategy* (unpublished), 2010.
- <sup>9</sup> Name withheld, Submission 757 to House of Representatives Standing Committee on Family, Community, Housing and Youth, *Inquiry into better support for carers*, 2009.
- <sup>10</sup> House of Representatives Standing Committee on Family, Community, Housing and Youth, 2009, p. 196.

- <sup>11</sup> Disability Investment Group, *The way forward: A new disability policy framework for Australia, Commonwealth of Australia*, 2009, p. 12.
- <sup>12</sup> Department of Families, Housing, Community Services and Indigenous Affairs, Portfolio Budget Statement, 2011-12. This figure includes Wife Pension (Disability Support Pension).
- <sup>13</sup> House of Representatives Standing Committee on Family, Community, Housing and Youth, 2009, p. 182.
- <sup>14</sup> House of Representatives Standing Committee on Family, Community, Housing and Youth, 2009, pp. 73 and 247.
- <sup>15</sup> Name withheld, *Submission 54 from nationwide consultations for developing the National Carer Strategy* (unpublished), 2010.
- <sup>16</sup> House of Representatives Standing Committee on Family, Community, Housing and Youth, 2009, p. 228.
- <sup>17</sup> House of Representatives Standing Committee on Family, Community, Housing and Youth, 2009, p. 228.
- <sup>18</sup> Carers Australia, *Young carers research project*, 2002, p. 2.
- <sup>19</sup> Australian Bureau of Statistics, *A profile of carers in Australia*, 2008.
- <sup>20</sup> House of Representatives Standing Committee on Family, Community, Housing and Youth, 2009, p. 237.
- <sup>21</sup> Name withheld, *Submission 145 from nationwide consultations for developing the National Carer Strategy* (unpublished), 2010.



