Conduct and Context of the Inquiry

1.1 Australia’s 2.5 million carers make a significant contribution to society, often at considerable personal cost to themselves. Despite the positive aspects of providing care for a loved one in need, carers also frequently sacrifice their finances, careers, social networks and even their own health. Increasingly however, in the absence of adequate supports and assistance, carers are questioning the lack of life choices available to them and their capacity to sustain the caring role. Many carers have made it known that they are already in crisis. It is recognition of the current plight of carers, and predictions that in the near future the number of people requiring care will exceed the number of people able and willing to provide care, that have provided the impetus for the current inquiry.

1.2 The Inquiry into Better Support for Carers was referred to the House of Representatives Standing Committee on Family, Community, Housing and Youth on 14 May 2008. An advertisement calling for written submissions was placed in The Australian on 28 May 2008. Information on the Inquiry, including its terms of reference and on how to make a submission was available on the Parliament of Australia website. The Inquiry was also advertised through an extensive mail out to interested parties, including peak bodies and organisations, and state and territory governments.

1.3 At the outset of the Inquiry, the Committee Chair, Ms Annette Ellis MP (Member for Canberra), indicated that the Committee was particularly keen to hear first hand from carers themselves. Of the over 1300 written submissions to the Inquiry, some 1200 were from individuals, the vast majority of whom identified themselves as current or former carers. A list of submissions is provided at Appendix A. In addition, 24 documents were received as exhibits. These are listed at Appendix B.
1.4 The Committee held fourteen public hearings between July and December 2008, taking evidence from around 250 witnesses. More than half of the witnesses appearing at the public hearings were carers. Other witnesses were representatives of government departments and agencies, peak organisations, service providers and academics. A feature of many of the public hearings was the carers’ roundtable sessions. These sessions provided the opportunity for individual carers to describe their own experiences to the Committee and to present their views on ways in which the needs of carers could be better met. Details of the public hearings for the Inquiry are listed at Appendix C. Information on income support payments and supplementary payments as at 1 July 2008, including information on eligibility criteria, income and assets test thresholds is at Appendices D to F.

Context of the Inquiry

1.5 The Inquiry into Better Support for Carers has garnered its own sizeable and credible body of evidence. It is important to emphasise that it is the Inquiry’s own evidence which has informed the Committee’s deliberations during the Inquiry process and which has assisted the Committee to reach its conclusions.

1.6 However, it is also important to acknowledge that the Inquiry was conducted in a highly dynamic policy environment. Since the November 2007 election, the Australian Government has implemented several new initiatives and programs that have impacted either directly or indirectly on carers. The Australian Government has also initiated a number of major reviews of government policy, some of which may have important implications for carers.

1.7 In this dynamic environment, it is imperative that the implications of these parallel processes on the outcomes of the current Inquiry are acknowledged. In addition, a number of the issues that have emerged in evidence to this Inquiry have also been considered previously as part of other recent parliamentary inquiries or policy review processes. Where

---

1 In this report the term Australian Government is used whenever possible in preference to Commonwealth Government or Federal Government.

2 See for example: From March 2008, access to Utilities Allowance, a payment to assist with regular household bills, was extended to recipients of the Carer Payment.

3 See for example: The 2008-09 inquiry into Australia Future Tax System (the Henry Review), which encompasses the Pension Review (the Harmer Review).
this is the case, this report may make reference to the outcomes of these other inquiries and reviews.

1.8 Other background material for the report, including statistics and data on carers has been drawn from a range of sources, including government department/agency reports and research from government and non-government sources. These sources of information are identified in the text or referenced in footnotes.

1.9 While not intended to be an exhaustive or comprehensive list of all relevant initiatives, the following section of this chapter provides a brief overview of some of the current and significant policy reviews that have implications for carers.

**Current Australian Government Policy Reviews**

1.10 In providing an overview of Australian Government policy reviews that are relevant to the current Inquiry, consideration has been given to the interrelationship between the needs of carers and care receivers. In many cases, carers have commented that measures intended to meet the support needs of the care receiver, often also improve the capacity of the carers themselves to provide care. Therefore, while carers are the focus of the Inquiry, the overview below includes information on some policy initiatives which are principally intended to address the needs of care receivers, but are also likely to have significant consequences for carers.

**Inquiry into Australia’s Future Tax System**

1.11 On 13 May 2008, a major review of Australia’s future tax system was announced by the Treasurer, the Hon Wayne Swan MP. According to the review’s terms of reference:

> The comprehensive review of Australia’s tax system will examine and make recommendations to create a tax structure that will position Australia to deal with the demographic, social, economic and environmental challenges of the 21st century and enhance Australia’s economic and social outcomes.

---

4 See for example: Name withheld, Submission No 19, p 2; Ms J Bissett, Submission No 54, p 2; Ms A Hewat, Submission No 866, p 4; Ms L Thomas, Transcript of Evidence, 12 August 2008, p 48; Ms B Epstein-Fisch, Transcript of Evidence, 12 August 2008, p 88.

The review is being conducted under the auspice of a review panel chaired by the Secretary to the Treasury, Dr Ken Henry AC. The review, which involves community consultation, is being conducted in several stages over 2008 and 2009. The review panel will provide a final report to the Treasurer by the end of 2009.6

Pension Review

On 15 May 2008, and as part of the broader review of Australia’s taxation system, the Minister for Families, Housing, Community Services and Indigenous Affairs, the Hon Jenny Macklin MP, also announced a review of the pension system.7

The Pension Review, chaired by Dr Jeff Harmer, Secretary for the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) will:

... investigate measures to strengthen the financial security of seniors, carers, and people with disability.8

In August 2008, a Pension Review Background Paper was released to support the public consultation process.9 The paper provides information on the income support system and considers issues associated with the Pension Review’s three key terms of reference:

- the appropriate levels of income support and allowances;
- the frequency of payments; and
- the structure and payment of concessions or other entitlements.

The review which involves significant community consultation is being overseen by a reference group. The Secretary for FaHCSIA reported to the Treasurer and the Minister for Families, Housing, Community Services and Indigenous Affairs, through the Chair of the Australia’s Future Tax System Review Panel in late February 2009. At the time of writing, the
Review’s final report is not publicly available. However, it is anticipated that the Review’s findings will inform a reform package to income support and supplements, which may include reforms to Carer Payment, Carer Allowance, Disability Support Pension (DSP) and other allowances and concessions accessed by carers and care receivers. These reforms will be announced as part of the May 2009-10 Budget.

**Council of Australian Governments (COAG) Reform Agenda**

1.17 The Council of Australian Governments (COAG) is the peak intergovernmental forum in Australia. The role of COAG is to initiate, develop and monitor the implementation of policy reforms that are of national significance and which require cooperative action by Australian governments. In the 2008-09 Budget, the Australian Government through COAG, committed to implementing a more effective and efficient model of ‘modern federalism’ though a reform agenda.  

1.18 One of the items to be progressed under the agenda, is reform to the roles and responsibilities between the Australian Government and states and territory governments for:

- community and residential care services for aged people;
- community and residential care for people with disabilities; and
- community care and support services for people with mental illness.

1.19 The stated objective of this reform is to:

... help build seamless service systems to meet better the needs of the aged, people with disability, people with mental illness and their carers on a national basis.

1.20 According to the COAG Communiqué of 2 October 2008:

The development of a reform package will be underpinned by the following principles:

- **continuity of care for clients, which is responsive to changing needs:** delivered by seamless and responsive services tailored to changing care needs;

---

10 The Hon Wayne Swan MP & The Hon Lindsay Tanner MP, Budget: Australia’s Federal Relations *Budget Paper No. 3 2008-09*, pp 11-27.


simple access to services: delivered by streamlined assessment and eligibility criteria;

seamless transition of care for clients: delivered by an assurance of client choice to receive ongoing ‘care in place’, and smooth interfaces between care systems;

simplified accountability of governments to the community: delivered by clearer responsibility of levels of government for policy and service provision to a particular client group;

reform of roles and responsibilities should be budget-neutral for both levels of government: delivered by the transfer of current funding to mirror the transfer of responsibilities for service provision; and

creation of a national aged care system and national disability service system for community and residential care: delivered by strengthened policy responsibility for delivery of the spectrum of community and residential care services for a particular client group.\(^\text{13}\)

1.21 A Roles and Responsibilities Working Group has been established to progress the program of reforms and COAG has requested that specific proposals in relation to reforms to community mental health, disability services and aged care are brought to it for consideration in the first half of 2009.

National Disability Agreement

1.22 The COAG reform agenda has also included fundamental reform to Commonwealth-state funding arrangements. Reform has included rationalisation of Specific Purpose Payments (SPP) from over 90 to five or six SPPs, including one to cover the disability area supported by the National Disability Agreement (NDA).

1.23 The NDA, which on 1 January 2009 replaced the third Commonwealth State Territory Disability Agreement (CSTDA), provides an agreed framework between the Australian Government and state and territory governments for funding and administration of specialist disability support services.

1.24 In brief, under the NDA funding contributions for disability services are provided by the Australian Government and by state and territory governments. The states and territories have primary responsibly for the

---

administration of specialist disability support services, with the exception of employment services for people with a disability, which is the responsibility of the Australian Government.\textsuperscript{14}

1.25 Under the NDA, over the next five years, the Australian Government will provide $5.3 billion to the states and territories, including funding to assist state and territory government’s delivery of specialist disability services. Of this, $408 million will go to assist with the National Disability Reform Agenda. Some of the key reforms under consideration include:

- improved access to disability care including consideration of systems that provide a single point of access;
- nationally-consistent assessment processes and a quality assurance system;
- a renewed focus on early intervention and planning to ensure that clients receive the most appropriate and timely support;
- service providers will be better able to develop train and employ care workers;
- more consistent access to disability aids and equipment;
- a commitment by all levels of government to work together to better measure the level of unmet demand for disability services; and
- continued work on reform of roles and responsibilities in relation to community mental health, disability services and aged care.\textsuperscript{15}

**National Disability Strategy**

1.26 The development of a National Disability Strategy (NDS) was a 2007 election commitment by the Australian Government. The NDS is intended to provide a framework to address the complex needs of people with disabilities, their carers and families. The NDS will be developed by FaHCSIA in consultation with state and territory governments, and with disability and carer stakeholders.

1.27 In October 2008, FaHCSIA released a NDS discussion paper to support the consultation process. According to the discussion paper the NDS:

... aims to provide an enduring framework of targeted actions that addresses barriers and promotes a more inclusive and universally accessible society for the benefit of the entire community.

\textsuperscript{14} Council of Australian Governments, National Disability Agreement, pp 3-9.

The Strategy will set out a high level vision that will be underpinned by clear outcomes with actions, target dates and performance measures. The Strategy will align relevant policies and initiatives to help improve integration across governments and in related policy areas.

The National Disability Strategy will be an important mechanism to ensure that the principles underpinning the United Nations Convention on the Rights of Persons with Disabilities are incorporated into policies and programs affecting people with disability, their families and carers.  

1.28 During October and November 2008, FaHCSIA undertook a series of public consultations to give interested parties the opportunity to give input and feedback on the direction of the NDS. Input and comments could also be submitted in writing with a closing date of 7 January 2009. The outcomes of the consultations and key points from submissions will be summarised in a report in early 2009 and the NDS released in mid 2009. The NDS will also be informed by the National People with Disabilities and Carer Council, chaired by Dr Rhonda Galbally AO.

National Mental Health and Disability Employment Strategy

1.29 The development of a National Mental Health and Disability Employment Strategy has been initiated as part of the Australian Government’s broader Social Inclusion Agenda. The Strategy aims to address the barriers faced by people with disability and/or mental illness that make it harder for them to gain and keep work.

1.30 In the first quarter of 2008, the Department of Education, Employment and Workplace Relations (DEEWR) released a discussion paper for comment. During April and May of 2008, DEEWR held 13 face to face consultations that were open to the community and interested parties. As a result of the consultations, the following six priority areas to increase employment opportunities for people with a disability and/or mental illness were identified:

- improving disability employment services;


providing greater encouragement, assistance and support for people with disability wishing to re-enter the workforce;
• innovation;
• tackling employer misconceptions;
• increasing Australian Public Service employment of people with disability; and
• improving access to education and training.  

1.31 The National Mental Health and Disability Employment Strategy will be released later in 2009.

Disability Investment Group

1.32 On 23 April 2008 the Parliamentary Secretary for Disabilities and Children’s Services, the Hon Bill Shorten MP, announced the establishment of a Disability Investment Group (DIG). The DIG is chaired by Mr Ian Silk, Chief Executive of Australian Super, and has members with experience and knowledge of philanthropic investment.

1.33 The terms of reference for the DIG are to:
• Identify international best practice in leveraging greater investment in disability support.
• Identify opportunities to increase private sector involvement and investment in the funding of disability services and related infrastructure, including new innovations to develop alternative funding sources and arrangements for people with disability and their families; identify barriers to this and how they might be overcome.
• Identify current and potential avenues for philanthropic investment in disability support.
• Explore government assistance to encourage family and private investment in the provision of housing, education, employment, equipment and other support for people with disability.
• Consider, with the community and financial institutions, avenues for new products and services to assist families plan for the future of their child with a disability.
• Develop options for investment in housing for people with disability through private and shared equity.

- Develop ways to assist people with disability, their families and not-for-profit organisations to engage with the private sector to enable development of accommodation and support options.
- Identifying research reforms to encourage private sector engagement in research.\textsuperscript{20}

1.34 The DIG has sought advice and ideas that are relevant to its terms of reference from people with disability, their families and carers, and from organisations involved in any aspect of disability. The DIG will report to the Australian Government later in 2009.

**Recent or Current Australian Parliamentary Inquiries**

1.35 In addition to the policy initiatives described above, there has been a number of parliamentary committee inquiries conducted either by the House of Representatives or by the Senate where issues that are pertinent to the current Inquiry have been raised and considered. A brief overview of these inquiries is provided in chronological order according to the date of tabling.

1.36 In February 2005, the House of Representatives Standing Committee on Family and Community Services\textsuperscript{21} announced an inquiry into balancing work and family. The inquiry’s terms of reference included consideration of:

- the impact of taxation and other matters on families in the choices they make in balancing work and family life.

1.37 The inquiry report, tabled in December 2006, included consideration of the added pressures of balancing work and family responsibilities for people who care for a child with a disability or an aged family member.\textsuperscript{22}

1.38 During 2006, the Senate Standing Committee on Community Affairs conducted an inquiry into the funding and operation of the CSTDA. The inquiry’s terms of reference included consideration of:


\textsuperscript{21} The House of Representatives Standing Committee on Family and Human Services was the predecessor in the 41st Parliament to the current Parliament’s House of Representatives Standing Committee on Family, Community, Housing and Youth.

the appropriateness or otherwise of current Commonwealth/State/Territory joint funding arrangements, including an analysis of levels of unmet needs and, in particular, the unmet need for accommodation services and support; and

an examination of the ageing/disability interface with respect to health, aged care and other services, including the problems of jurisdictional overlap and inefficiency.

1.39 In February 2007 the Senate Committee tabled its report *Funding and operation of the Commonwealth State/Territory Disability Agreement*. The inquiry made 29 recommendations to underpin considerations for reform of the next CSTDA and to improve the delivery of specialist disability services. The primary recommendation was:

That Commonwealth, State and Territory governments jointly commit as part of the fourth CSTDA to substantial additional funding to address identified unmet need for specialist disability services, particularly for accommodation services and support.

1.40 Also in 2007, the House of Representatives Standing Committee on Legal and Constitutional Affairs conducted an inquiry into the adequacy of current legislative regimes and the legal needs of older Australians. Notably in relation to the current inquiry, the *Older People and the Law* report considered issues associated with substitute decision making. The report makes 13 recommendations in relation to improving legislative regimes and systems associated with substitute decision making.

1.41 In October 2008, the Senate Standing Committee on Community Affairs released its report on Special Disability Trusts (SDTs). SDTs were introduced in 2006 to assist parents and carers concerned about what would happen to a person with a disability when they were no longer able to provide care. The lower than anticipated take-up of SDTs, and concerns about their operation expressed by carers and families provided the impetus for the inquiry.

---


1.42 The Committee’s report, *Building trust: supporting families through Disability Trusts* makes 14 recommendations intended to increase awareness of the trusts, and improve the operation of the Trusts by reducing the complexity and costs of establishing and maintaining a SDT.\(^{26}\)

1.43 In December 2008, the House of Representatives Legal and Constitutional Affairs Committee also announced an inquiry to examine the *Draft Disability (Access to Premises - Buildings) Standards*.\(^{27}\)

1.44 The draft standards were developed by the Australian Building Codes Board and the Australian Human Rights Commission. The standards are intended to make public buildings more accessible for people with mobility, vision and hearing impairments. The terms of reference for the inquiry included a requirement for the Committee to inquire into and report on:

> The appropriateness and effectiveness of the proposed Premises Standards in achieving their objects.\(^{28}\)

1.45 The Committee will report on its finding later in 2009.

### Key Themes Emerging from this Inquiry

1.46 The nature of the Inquiry has been such that many of the written submissions and verbal testaments from carers have involved detailing what are frequently very personal, and sometimes distressing, experiences. While not able to investigate specific grievances raised by carers or intervene in individual cases, the Committee found this body of evidence to be compelling and highly illustrative of the day-to-day challenges faced by many carers. The Committee used these personal stories to identify the common themes emerging from the evidence and to focus its attention on the reforms to government policy and practical steps that it could recommend to improve the lives of carers and their families.

1.47 In synthesising the evidence from the Inquiry the following broad themes emerged:


lack of recognition of the role and contribution that carers make to society and absence of a national and strategic approach to supporting carers and their families;

difficulties in accessing necessary and relevant information on the supports and services available to carers and lack of assistance for carers to develop the range of skills needed to support them in their role;

financial stresses facing many carers and their families as a consequence of opportunity costs\(^\text{29}\), the level of government financial assistance and the additional costs of disability and caring;

dissatisfaction with the community care systems. Specifically, evidence highlighted significant concerns in relation to the complexity of systems, the level of unmet need, the costs of accessing services, inflexible delivery of services and in some cases, the questionable quality of care;

lack of choice for carers in relation to participation in the workforce and/or education, primarily due to shortages of respite or alternative care options for the care receiver and inflexible workplace practices; and

the physical, emotional and social impacts of caring on the health and wellbeing of carers and families.

Structure of the Report

1.48 The broad themes identified above have provided the basis for the structure of the report. It should be noted that the order of presentation of the chapters is not intended to be indicative of any judgement of the comparative importance of the issues.

1.49 Following the context presented in this chapter, chapter 2 provides a broad overview of background information on the carer demographics and on the government carer supports and services. The remainder of the report comprises the following chapters:

- chapter 3: A National and Strategic Approach to Carer Recognition and Policy;

\(^{29}\) The income forgone by carers providing care rather than participating in paid employment.
• chapter 4: Information, Skills and Capacity Building;
• chapter 5: Financial Assistance;
• chapter 6: Access to Supports and Services;
• chapter 7: Employment and Education; and
• chapter 8: Health and Wellbeing.

1.50 In addition, although the terms of reference for the Inquiry indicated that the Committee will inquire into the needs of particular groups within the caring population, as the Inquiry has progressed the multiplicity of carer groups has become increasingly evident. While not intended to be an exhaustive list of all possible carer groups, in addition to those groups identified in the terms of reference (i.e. new carers, younger carers, older carers, Indigenous carers and those with multiple care responsibilities), evidence has been received from long-term carers, former carers, carers of people with a mental illness, carers living in regional and remote locations, working carers, male carers, grandparent carers and foster parent carers.

1.51 Given that the majority of issues considered in the report are broadly relevant to all carers, the report does not seek to address the specific needs of particular carer or care receiver groups in separate chapters. Rather, where issues have additional relevance to specific carer or care receiver groups this will be emphasised in the text.

1.52 In considering the many issues raised in evidence, the compelling need for significant and fundamental reforms to the system of supports and services for carers and care receivers has emerged. To some extent the need for significant reform is reflected by the large number of reviews of government policy and by the current reform agendas described earlier in this chapter. However, the development and implementation of systemic reform is likely to require a significant period of time. In recognition of this, while the report contains some recommendations intended to promote longer term fundamental systemic reform, its also includes other recommendations which address the most pressing and frustrating aspects of the current system which will give immediate relief to carers in the shorter term.

1.53 Evidence to the Inquiry has provided a snapshot of the personal and lived experiences of over 1200 carers living throughout Australia. As the Committee is keen for the report to provide a platform for the voice of carers, the report makes extensive use of excerpts from submissions and transcripts, enabling carers to tell their own stories in their own words.