



# **Taskforce on Care Costs**

## ***2007 Report***

### ***The hidden face of care: Combining work and caring responsibilities for the aged and people with a disability***

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## Executive Summary

The Taskforce on Care Costs (TOCC) was established in November 2003 to investigate the financial cost of care and how it affects workforce participation, and to promote reforms within a policy framework of (i) financial sustainability; (ii) equity; and (iii) choice. TOCC is supported by over 45 key Australian business and non-government stakeholders<sup>1</sup>.

Between 2005 and 2006 TOCC released three major research reports which made the case for immediate action to improve the work/care dynamic. In essence these reports made the macro business case for change by identifying the direct relationship between reduced workforce participation and the high cost of care, and proposing financial policy reforms to alleviate this tension.

Given that 2007 is a Federal election year, and the central importance of public policy reforms to assist working carers to better balance their work and caring responsibilities, TOCC has focussed on raising political awareness of the groundswell of community support for reform, and conducting micro research on the nature of the work/care dynamic.

In regard to raising political awareness, TOCC has commissioned two national Newspoll surveys to identify the relationship between policy reforms and voting patterns. The survey conducted in March 2007 found that

*87% of Australians surveyed said that the Federal Government should increase financial support for carers, and 77% said that it would influence their voting choice<sup>2</sup>.*

The survey conducted in October 2007 found that

*29% of Australians surveyed said that they would be "a lot more likely" to vote for one of the major parties if a commitment was made to provide additional support to people who provide care to the aged or a person with a disability<sup>3</sup>.*

With regard to conducting micro research, in 2007 TOCC has conducted a research programme to provide a finer level of detail on the work/care dynamic. In this regard TOCC initially focussed on childcare, and in March 2007 launched Australia's first Childcare Affordability Index. The CAI demonstrated that the cost of childcare has become increasingly unaffordable, and has risen by 65% in the past five years in comparison to a 17% increase in disposable income.

The launch of the current report "*The hidden face of care: Combining work and caring responsibilities for the aged and people with a disability*" provides detailed

<sup>1</sup> AAMI, Aequus Partners, AMP, ANZ Bank, Australian Women Lawyers, Bendigo Bank, Blake Dawson, BlueScope Steel, Carers Australia, Ernst & Young, Eskimo Productions, Families Australia, Freehills, Early Years Parents and Friends, Gillard Consulting Lawyers, Goldman Sachs JBWere, Hewitt, HSBC, Hudson, IAG, ING, Jones Lang LaSalle, KPMG, Mallesons Stephen Jaques, McDonalds (Australia), National Australia Bank, Orijen, Parker & Partners, Qantas, Reuters, Rialto Consulting, Swiss Reinsurance, Telstra, The Australian Stock Exchange, The Bar Council of NSW, The Equal Employment Opportunity Network of Australasia, The Human Rights and Equal Opportunity Commission, The Law Society of NSW, The NSW Equal Employment Opportunity Practitioners' Association, Toyota, WeeWunz, Westpac Banking Corporation, Women in Finance, Wilkinson Media, Women Lawyers Association of NSW, Working Carers Support Gateway, Work/Life Association.

<sup>2</sup> On 16-18 March 2007 Newspoll administered a survey on behalf of TOCC to 1204 Australians aged 18 years+. See TOCC *It's official: The cost of care is an election decider*, Media release, 29 March 2007 [www.tocc.org.au](http://www.tocc.org.au).

<sup>3</sup> See TOCC *Missing the picture: The election is about work AND family*, Media release 18 October 2007 [www.tocc.org.au](http://www.tocc.org.au).



information on the work/care dynamic for carers of the aged and/or people with a disability. In particular, the aim of this report is to provide a holistic picture of the experience of combining work and aged and/or disability care, ie one which includes the financial cost of care *and* the personal, community and economic impacts of care on workforce participation.

In essence *The hidden face of care* finds that although public rhetoric acknowledges the need to help carers of the aged and people with a disability to balance their work and caring responsibilities, in reality tangible support is insufficient and ineffective. This is evident in relation to public policy (eg legislation, financial support and service provision) as well as workplace policy and practices. As a consequence of the mismatch between rhetoric and reality, carers of the aged and/or people with a disability are much less likely to participate in the paid workforce, and at a level commensurate with their skills and qualifications. The marginalisation of carers is patently inequitable and poses an immediate and growing threat to Australia's continued economic prosperity.

In summary, *The hidden face of care* exposes the need for urgent attention by policy makers and employers to relieve the current work/care tensions experienced by Australians caring for a person who is aged and/or has a disability. The need for reform will become increasingly acute as the Australian workforce faces the dual pressures of an increasing skill shortage and a decreasing caretaker ratio.

To help address these issues, *The hidden face of care* makes the following findings about the nature of the work/care dynamic, and recommendations for change.

#### **Key findings in relation to combining work and aged and/or disability care**

1. **Being valued:** Carers currently feel undervalued, and that their experiences are misunderstood by employers and co-workers. This is reflected in the minimal level of service provision, as well as financial and workplace supports.
2. **Experience difficulties:** Carers experience difficulties balancing work and caring responsibilities: 34% of carers surveyed say that their job/career has suffered because of the competing demands of their caring responsibilities.
3. **Inadequate services:** Carers feel that support services are inadequate and fractured across Government departments, as well as Federal and State/Territory Governments.
4. **Costly services:** Government financial supports for carers are viewed as welfare, and not as a strategy to enable workforce participation. Accordingly financial supports are insufficient and 1 in 4 carers of the aged and/or people with a disability have reduced their hours of work because of the cost of care.



5. **Underuse of resources:** Carers represent an under-utilised workforce resource: nearly half (44%) of the carers surveyed chose a role below their skill level because it gives them the flexibility they need to balance work and caring responsibilities.
6. **Priority strategies:** The strategies which would most assist carers to balance their work and caring responsibilities are (i) improved access to support services; (ii) greater workplace flexibility; and (iii) improved quality of support services.
7. **Workplace flexibility:** Carers find it difficult to access the full range of flexible work practices, and implementation varies across and within organisations.
8. **An issue for now and the future:** 1 in 4 Australians surveyed expect to care for an aged person and/or a person with a disability in the next 5 years, and workplace flexibility will be their key management strategy. 70% of respondents would like to manage these responsibilities by working more flexible hours, more than half (54%) by reducing their work hours, 50% by taking leave, and 41% by working from home.
9. **A strategic approach:** Resolving the dual work and care pressures more effectively requires a strategic and planned approach which integrates service provision, financial policies and workplace flexibility. This requires leadership, and co-operation, by Government, employer and carer stakeholders.
10. **A new legislative framework:** Current Federal anti-discrimination law does not provide sufficient protections for employees with caring responsibilities, nor impetus for the implementation of flexible work practices. Recent initiatives in the United Kingdom, including the introduction of legislation which provides employees with a "right to request" and employers with a duty not to "unreasonably refuse" such a request, provide Australia with a best practice model for change.

#### **Key recommendations in relation to combining work and aged and/or disability care**

1. **Service provision:** The Government/Opposition develop strategies to enhance access to, and the quality of, aged and disability services. These strategies should ensure the greater integration and resourcing of services.
2. **Workplace flexibility:** Employers ensure greater access to the full range of flexible work practices (ie beyond part-time work) for all carers (ie beyond the current focus on childcare). In addition, employers work towards greater consistency of implementation by managers across their organisations.
3. **Financial supports:** The Government/Opposition commit to increasing the level of financial supports for employees who are concurrently caring



for an aged dependent and/or a person with a disability to enable real choices to be made about work and care.

4. **Legislation:** The Government/Opposition commit to introducing a Family Responsibilities and Carers' Rights Act, as recommended by the Human Rights and Equal Opportunity Commission.
5. **Review:** The Government/Opposition commit to conducting a comprehensive review of public policy and employment strategies to assist employees to balance their work and caring responsibilities for the aged and people with a disability. This review should be conducted in concert with State, Territory and Federal Governments, aimed at creating a whole-of-government approach to enhancing service provision, and responsive to local and regional settings. It is recommended that the review committee comprise representatives from Governments (Federal, State/Territory), carer organisations, businesses and other interested parties. The aim of the review committee should be to launch a strategic plan, with specific actions, by 25 November 2008.



## 1. Introduction

The Taskforce on Care Costs (TOCC) was established in November 2003 to investigate the financial cost of care and how it affects workforce participation, and to promote reforms within a policy framework of (i) financial sustainability; (ii) equity; and (iii) choice. TOCC is supported by over 45 key Australian business and non-government stakeholders<sup>4</sup>.

Between 2005 and 2006 TOCC released three major research reports which made the case for immediate action to improve the work/care dynamic. In essence these reports made the macro business case for change by identifying the direct relationship between reduced workforce participation and the high cost of care, and proposing financial policy reforms to alleviate this tension.

In 2007 TOCC has focussed on raising political awareness of the groundswell of community support for reform, and conducting micro research on the nature of the work/care dynamic. This micro research agenda initially focussed on providing a finer level of detail on the relationship between work and childcare costs. The current report, *The hidden face of care*, provides a finer level of detail on the relationship between *work and aged and/or disability care*. This level of detail is intended to enhance the understanding of Government policy makers and employers about the work/care dynamic and stimulate appropriate reforms.

This introductory chapter sets the scene for the specific findings and recommendations of *The hidden face of care*, by (i) reviewing TOCC's research findings and recommendations to date; (ii) highlighting TOCC's 2007 awareness raising strategy; and (iii) TOCC's 2007 programme of micro research.

### 1.1 Background research findings and recommendations (2005-2006)

Between 2005 and 2006 TOCC released three major research reports: The first report (2005) "*Creating Choice: Employment and the Cost of Care*" made the case for the direct and causal relationship between the cost of care and workforce participation; the second report (2006) "*Where are we now?*" provided a status report on the current cost of care/workforce participation landscape in Australia, and concluded that strong leadership, and immediate intervention, is required to improve the work/cost of care dynamic in Australia. The third report (2006) "*Where to now?*" proposed economically modelled solutions to increase Government financial support for carers.<sup>5</sup>

In summary the five key findings from TOCC's previous research reports are:

1. *There is a clear relationship between work and the cost of care:*
  - 1 in 4 employees with caring responsibilities is likely to leave the workforce because the cost of care is too high.

<sup>4</sup> AAMI, Aequus Partners, AMP, ANZ Bank, Australian Women Lawyers, Bendigo Bank, Blake Dawson, BlueScope Steel, Carers Australia, Ernst & Young, Eskimo Productions, Families Australia, Freehills, Early Years Parents and Friends, Gillard Consulting Lawyers, Goldman Sachs JBWere, Hewitt, HSBC, Hudson, IAG, ING, Jones Lang LaSalle, KPMG, Mallesons Stephen Jaques, McDonalds (Australia), National Australia Bank, Orjen, Parker & Partners, Qantas, Reuters, Rialto Consulting, Swiss Reinsurance, Telstra, The Australian Stock Exchange, The Bar Council of NSW, The Equal Employment Opportunity Network of Australasia, The Human Rights and Equal Opportunity Commission, The Law Society of NSW, The NSW Equal Employment Opportunity Practitioners Association, Toyota, WeeWunz, Westpac Banking Corporation, Women in Finance, Wilkinson Media, Women Lawyers Association of NSW, Working Carers Support Gateway, Work/Life Association.

<sup>5</sup> All three reports are available on [www.tocc.org.au](http://www.tocc.org.au)



- 1 in 4 employees with caring responsibilities has already reduced their hours of work because the cost of care is too high.
2. *Employees will act on the cost of care dilemma*
    - In 2006 the cost of care influenced the departure of 64% of unemployed carers from the workforce.
  3. *Employees with caring responsibilities want real choices*
    - 35% of employees with caring responsibilities would increase their hours of work if care was more affordable.
    - 60% of unemployed carers would re-enter the workforce if care was more affordable.
    - 52% of part-time employees would increase their hours of work if care was more affordable.
  4. *The situation is getting worse, not better*
    - In 2006 the CPI increased by 4%, but care costs (for children, the elderly and people with a disability) increased by 10%.
    - In 2006 79% of employees with caring responsibilities said that affordability of care influenced their current working relationships, up 12% from 67% in 2004.
  5. *Current financial supports for Australians with caring responsibilities are inadequate in terms of level and coverage*
    - The Child Care Tax Rebate (CCTR) covers 30% of out-of-pocket expenses and is capped at \$4000 pa.
    - 75% of Australians with caring responsibilities believe their care costs should be shared equally with Government.
    - 77% of Australians with caring responsibilities believe that there should be a range of delivery options for additional financial support – ie (i) payments directly to the carer; (ii) payments directly to the care service provider; or (iii) via an employer (eg FBT).
    - 93% of Australians with caring responsibilities believe the CCTR should be extended to elder and disability care.

Based on economic modelling by the Melbourne Institute, and TOCC's research data, in 2006 TOCC recommended to Government two primary solutions to address the work/cost of care crisis, namely the introduction of:

- A 50% Care Costs Reimbursement (CCR) for out-of-pocket expenses up to \$10,000 pa per household; and
- Multiple delivery mechanisms for the CCR, ie to the employee, to the care service provider and to the employer (eg via salary sacrifice).

## **1.2 2007 – TOCC's awareness raising strategy**

Given that 2007 is a Federal election year, and the central importance of public policy reforms to assist working carers to better balance their work and caring responsibilities, TOCC has focussed on raising political awareness of the groundswell of community support for reform.





Part of the strategy to raise political awareness comprised TOCC's "Who Cares?" e-campaign in February-March 2007. The campaign enabled Australians to (i) logon to TOCC's website to view interviews with key stakeholders (in relation to childcare, aged care and disability care) and on-the-street interviews with everyday Australians, and (ii) send over 2,300 e-cards to Government and Shadow Ministers expressing their concerns about the high cost of care.

TOCC also commissioned two Newspoll surveys to identify the relationship between community concern about the work/care dynamic and voting intentions.

The first survey<sup>6</sup> (conducted in March 2007), which focussed on the *cost of care for child, aged and disability care*, identified that 87% of Australians surveyed believe the Federal Government should increase its financial support for carers (of children, the elderly or people with a disability) to help them take up or remain in paid employment. Moreover, 73% of Australians surveyed said that providing such support is important to how they will vote at the next Federal election (on 24 November 2007). The results also demonstrated that the cost of care is important to voters of both major political parties<sup>7</sup>, leading TOCC to conclude that the cost of care is the national leveller.

The second survey<sup>8</sup> (conducted in October 2007), which focussed on *general support carers of the aged and people with a disability* found that 29% of voters would be "a lot more likely" to vote for a particular party if that party made a commitment to providing additional support to carers of the aged and/or people with a disability. That finding was the same for men and women, leading TOCC to conclude that voter support for aged and disability care cuts across gender lines.

### 1.3 Micro research

Having made the macro case for the introduction of financial reforms to enable carers to better balance their work and caring responsibilities, in 2007 TOCC embarked upon a programme of micro research to provide a finer level of detail on the relationship between work and care. TOCC initially concentrated on gaining a deeper understanding of the work/childcare dynamic before turning to aged and disability care.

Firstly, in relation to the work/childcare dynamic, a key gap in Australia's knowledge was whether and if so how, the affordability of childcare has changed over time. Accordingly, in March 2007 TOCC launched Australia's first Childcare

<sup>6</sup> On 16-18 March 2007 Newspoll administered a survey on behalf of TOCC. The survey asked 1,204 Australians aged 18+ (i) whether the Federal Government should increase its financial support for carers to help them take up or remain in paid employment, and (ii) whether the issue of providing financial support is important to how they will vote at the next Federal election. A survey of 1,204 represents the views of 15.8 million Australians. See TOCC *It's official: The cost of care is an election decider*, Media release, 29 March 2007 [www.tocc.org.au](http://www.tocc.org.au).

<sup>7</sup> 77% of Labor voters and 65% of Coalition voters said that the cost of care is important to their voting choice at the next Federal election.

<sup>8</sup> On 13-14 October 2007 Newspoll administered a survey on behalf of TOCC. The survey asked 1,234 Australians aged 18+ to think about people who have caring responsibilities for the elderly, people with disabilities or chronic health conditions (as an informal job), and whether a commitment by one of the major parties to provide additional support would make them more or less likely to vote for that party, or make no difference. In total 55% of respondents said that such a commitment would make their vote more likely, comprising 29% "a lot more likely" and 26% "a little more likely". See TOCC *Missing the picture: The election is about work AND family*, Media release 18 October 2007 [www.tocc.org.au](http://www.tocc.org.au).



Affordability Index (CAI). Modelled on the Consumer Price Index, and based on Australian Bureau of Statistics data, the CAI demonstrates that between June 1990 and June 2006 childcare costs increased by 123% whilst average household disposable income increased by 62%. Disturbingly, over the last 5 years alone childcare costs have increased by 65% whilst average household disposable income has increased by only 17%. Positively however, the CAI demonstrates that increased levels of Government financial support in 1991 and 2000 had a positive impact on the affordability of care, leading TOCC to conclude that Government policy plays a key role in correcting affordability trends.

Secondly, in relation to aged and disability care, TOCC recently formed a partnership with Families Australia and Carers Australia, to conduct research on the impact of aged and disability care on the workforce participation of carers, as well as strategies to address these issues. The findings and recommendations from that research are presented in this report.

The methodology for this research comprised:

1. A literature review of current financial and policy supports for working carers, both domestically and internationally;
2. Quantitative research, namely a random sample national survey (conducted by Newspoll) of working age Australians, and working carers (of the aged and people with a disability), on the relationship between work and care, and remedial strategies; and
3. Qualitative research, namely the conduct of five focus groups with working carers and a roundtable with experts from peak carer groups, to elicit the voices of formal and informal carers on the experience of the work/care dynamic and options for improvement.

The findings from this research are presented across three chapters covering (i) the policy landscape in Australia; (ii) facts and figures; and (iii) the voices of formal and informal carers. Conclusions are drawn at the end of each chapter, and these are integrated into ten key findings in the final chapter along with five recommendations for action.

### **1.5 Summary**

Whilst Australians currently do have access to a level of economic support for their caring responsibilities, clearly there is an unmet need. In particular TOCC's previous research has demonstrated a clear relationship between reduced levels of workforce participation and the high cost of care. TOCC has also demonstrated that this is an unwanted outcome for both employers and employees with caring responsibilities, and puts at risk Australia's continued economic prosperity. The level of concern about correcting the current state of play is evident in voter responses to the question of whether the Government should provide additional financial support to relieve the cost of care.

Voter responses also indicate a high level of concern about the levels of support for informal carers of the aged and people with a disability. To enable the Government and Opposition to develop appropriate policy and legislative responses to these concerns, this report provides a detailed analysis of the current state of play, and identifies priority areas for reform.



## 2. The policy landscape in Australia

This chapter provides an overview of the current demographic and workplace drivers impacting the work/care dynamic and describes the current state of play in relation to policy and financial supports in Australia. The aim of this information is to help analyse whether Australian Government and workplace policies are meeting the current and projected needs of working carers. Building on the findings of previous TOCC reports (as described in chapter 1), TOCC finds that there is a growing gap between the needs of working carers for support to help manage their work and caring responsibilities, and their daily reality. In order to provide fresh thinking on solutions to help bridge this gap, TOCC reviewed international initiatives to address the work/care dynamic for aged and disability care, and the final section of this chapter highlights the approach recently adopted by the UK Government to enhance the experience of working carers.

### 2.1 Demographic and workplace drivers

Over the past 20 years, the Australian population and labour force have undergone major structural changes. Reduced numbers of young entrants into the labour market, an increase in the retention (and re-entry) of mature age employees, and the increase in women's participation rates have all contributed to changes in the composition of the workforce.<sup>9</sup> In addition, Australia is currently experiencing labour shortages, particularly in relation to skilled labour, which is putting pressure on employers to retain current talent, and attract new pools of talent<sup>10</sup>.

By way of further detail, the following demographic trends are contributing to the dual work/care pressures that Australia is currently experiencing:

- (i) *The Total Fertility Rate* (TFR – is the number of children a woman would bear during her lifetime if she experienced the current age-specific fertility rates at each age of her reproductive life) is currently 1.8 births per woman, almost half the peak rate of 3.5 birth per woman in 1961. While this is expected to increase slightly in the short term, by 2047 the TFR is projected to be 1.7 births per woman<sup>11</sup>. These data mean that there will be a lower birth rate and consequently a lower proportion of young people will be entering the workforce.
- (ii) *Increased life expectancy* - a man aged 60 in 2007 is expected to live a further 22.6 years. By 2027 this is expected to increase to 25.5 years and by 2047 to 27.7 years. A woman aged 60 in 2007 is expected to live a further 26.1 years. By 2027 this is expected to increase to 28.6 years and by 2047 to 30.8 years<sup>12</sup>.
- (iii) *Increased proportion of older Australians* - currently 13.4% of the population are 65 years or over (including 1.7% aged 85 or older). By 2027 this is projected to increase to 20.5% (including 2.7% aged 85 and older) and by 2047 to 25.3% (including 5.6% 85 years or older). In contrast, 67.5% of the population are currently between the ages of 15 and 64 (the

<sup>9</sup> NATSEM (2005) *May the labour force be with you. Changing face of the Australian labour force 1986-2005*, AMP.NATSEM Income and Wealth Report Issue 12, November 2005, [www.amp.com.au](http://www.amp.com.au), p. 25.

<sup>10</sup> DEWR (2005) *Workforce tomorrow. Adapting to a more diverse Australian labour market*, Australian Government.

<sup>11</sup> The Treasury, *Intergenerational Report 2007*, part 2, p. 2.

<sup>12</sup> The Treasury, *Intergenerational Report 2007*, part 2, p. 4.



traditional working ages) but this is expected to decrease to 62.7% by 2027 and 59.7% by 2047<sup>13</sup>. These data mean that Australians are expected to live longer resulting in a larger proportion of population aged 65 or older.

- (iv) *Higher proportion of females with higher qualifications than males* - in 2006, 22.7% of males between the ages of 25 and 64 years had attained a bachelor degree or higher with a further 7.9% having attained either an advanced diploma or a diploma. However 24.8% of females between these ages had attained a bachelor degree or higher with a further 10.5% of females having attained either an advanced diploma or a diploma.<sup>14</sup> These data mean that females comprise a key part of Australia's skilled labour given that a higher proportion of females have diploma or associate diploma qualifications or above than males.
- (v) *Increased labour force participation for females compensating for decreased participation by males* - currently the labour force participation rate for people aged 15 or over is 64.8. Between 1999 and 2007 the male labour force participation rate for males aged 15 or over has decreased slightly from 72.7% to 72.2% while unemployment has decreased to 7.6% to 4.3%. In contrast, the female labour force participation rate increased from 53.8% to 57.6% while unemployment decreased from 7.0% to 4.8%<sup>15</sup>. As noted by the Business Council of Australia the increase in female participation is strongly related to increase in part-time employment, with women accounting for 72% of all part-time workers in 2005<sup>16</sup>. These data mean that recent increases in labour force participation rates are due to increases in female participation.
- (vi) *Projected increases in participation for people aged 15-64* - according to the Intergenerational Report 2007, the labour force participation of people aged 15-64 years is expected to rise from 76.2% in 2006-07 to 78.1% in 2046-2047, mainly due to an increase in older workers, with female participation rates expected to increase for women of all age groups, particularly older women<sup>17</sup>. These data mean that the trend is towards increasing labour force participation rates, particularly among older workers.

Some of the labour force pressures and skill deficits could be relieved by the increased participation rates of carers. As TOCC's previous research has demonstrated, this would be a welcome outcome for many carers and employers. Militating against this outcome is the increasing pressure on informal carers to provide more care, and fewer carers will be available to meet those demands. Modelling conducted by the National Centre for Social and Economic estimates that the current caretaker ratio (ie the number of people most likely to provide care: the number of people needing care) is expected to fall from 2.5:1 to 1.5:1 over the next 20 years, and to 1:1 over the next 35 years.

<sup>13</sup> The Treasury, *Intergenerational Report 2007*, part 2, p. 4.

<sup>14</sup> Australian Bureau of Statistics, *Australian Social Trends 2007*, Cat No. 4102.0, p. 2.

<sup>15</sup> Australian Bureau of Statistics, *Labour Force, Australia*, Cat No. 6202.0.

<sup>16</sup> Business Council of Australia, (2006) *Employing Our Potential: Ensuring Prosperity Through Participation*, p. 36.

<sup>17</sup> The Treasury, *Intergenerational Report 2007*, part 2, p. 9-10.



In summary, Australia is experiencing dual and apparently conflicting pressures, namely to increase labour supply as well as carer supply, and these are predicted to increase in intensity. These pressures are being played out in the lives of working carers, and the experiences of employers, as demonstrated in the following section.

## 2.2 Caring and its impact on carers' labour force participation

In 2003, it was estimated that 2.56 million people, or 12.9% of the population, provided informal care to a person who is aged and/or has a disability, including 474,600 people who were primary carers (providing the majority of care to another person)<sup>18</sup>. The majority of all carers are female (54.1%), with 59.9% of female carers and 52% of male carers aged between 35 and 64 years.<sup>19</sup>

The House of Representatives Standing Committee on Family and Community Services ("Standing Committee") reported that as people reach the age of 80 the likelihood that they will significant care increases.<sup>20</sup> As the Standing Committee noted:

*The ageing population, combined with the increased age at which mothers give birth, means that many parents are now faced with the responsibility of looking after their own parents as well. These parents are now called the 'sandwich generation'.<sup>21</sup>*

Access Economics, in a report for Carers Australia entitled, *The Economic Value of Informal Care*, reported that the labour force participation rates for all carers (in 2005) was 56.1% compared to 67.9% for people without caring responsibilities.<sup>22</sup> However, when considering primary carers, the labour force participation rate is only 39%, with participation in full-time employment only "19.2%, less than half that of the general population".<sup>23</sup> The Standing Committee, in its report on the inquiry into balancing work and family noted that being a primary carer reduces the likelihood of workforce participation by 30%.<sup>24</sup>

Considering the ageing of the population and the fact that the majority of carers are aged 35 to 64 years, it is expected that without significant positive action to improve the ability of carers to participate in the workforce, the low participate rate will continue and likely further reduce.

This is particularly likely to impact female employees, particularly those aged 45-65 years of age, who have traditionally been tasked with caring<sup>25</sup>. Yet, as noted above, the labour market is increasingly reliant on this pool of talent, and projections for the future workforce rely on additional increases in female participation rates, particularly for older working age females. Further whilst there are predicted ongoing skill shortages in 2003 it was estimated that 47.9% of

<sup>18</sup> Access Economics, *The Economic Value of Informal Care*, August 2005, p. 1.

<sup>19</sup> Access Economics, *The Economic Value of Informal Care*, August 2005, p. 1.

<sup>20</sup> House of Representatives, Standing Committee on Family and Human Services, *ibid*, p. 273.

<sup>21</sup> House of Representatives, Standing Committee on Family and Human Services, *ibid*, p. 273.

<sup>22</sup> Access Economics, *The Economic Value of Informal Care*, August 2005, p. 11.

<sup>23</sup> Access Economics, *The Economic Value of Informal Care*, August 2005, p. 12.

<sup>24</sup> House of Representatives, Standing Committee on Family and Human Services, *ibid*, p. 275.

<sup>25</sup> AMP.NATSEM (2005) *May the labour force be with you. Changing face of the Australian labour force 1985-2005*, AMP.NATSEM Income and Wealth Report Issue 12, November 2005, www.amp.com.au



carers had a qualification at Certificate level or above, only marginally below that of non-carers (50.8%)<sup>26</sup>, indicating a largely untapped source of skill. However under the current care model, with the projected higher proportion of older Australians, the likelihood is that more working age people will be required to provide care, including primary care, which will negatively impact labour force participation.

The dilemma is finding a balance between the dual pressures of work and care. The above data on negative workforce outcomes leads TOCC to conclude that there is a lack of balance between these two pressure points. This conclusion is fortified by data on outcomes for carers in terms of poverty and well-being. In relation to poverty, carers' lower labour force participation rates, and particularly for full-time employment, results in 45% of primary carers having household incomes in the two lowest income quintiles of income ranges, compared to 23% for non-carers<sup>27</sup>. This is largely due to 47% of primary carers relying on Government pensions and allowances as their main source of income, compared to 16.3% of non-carers<sup>28</sup>. Only 34% of primary carers and 52.4% of other carers received wages or salary, compared to 59.5% of non-carers<sup>29</sup>.

In relation to well-being outcomes, the low household income of many carers has significant impacts on their quality of life and well-being. The largest survey of carers' health and well-being was undertaken by Deakin University as part of the Australian Unity Well-being Index and released in October 2007. Findings from the 4,000 respondents indicated that carers have the lowest collective wellbeing of any group surveyed over the past six years. However, carers receiving Centrelink payments had an even lower wellbeing than carers not receiving these payments<sup>30</sup>.

A critical part of the solution to resolve the current work/care challenge is to provide appropriate public and workplace supports. These supports will enable carers to make real choices about how they balance work and caring for the aged and/or people with a disability. In particular TOCC expects that such supports will lift the workforce participation of carers, thus filling Australia's current (and projected) skill gaps.

The key questions therefore are (i) do current public and workplace policies provide a sufficient level of support to enable carers to ably balance their work and caring responsibilities?; and (ii) is the current model of support appropriate?

### 2.3 Employed carers – Where is the support?

Whilst TOCC has a history of focussing on the impact of the *financial* cost of care on workforce participation, and therefore the adequacy of Government funding, the research undertaken for this report clearly identified the simultaneous importance of broader public policy and workplace adaptation. Accordingly, this

<sup>26</sup> Carers Australia (2004), *Fact Sheet*, p. 3 (relying on data from the ABS (2003) Survey of Disability Ageing and Caring [www.carersaustralia.com.au](http://www.carersaustralia.com.au)).

<sup>27</sup> Carers Australia (2004), *Fact Sheet*, p. 3 [www.carersaustralia.com.au](http://www.carersaustralia.com.au).

<sup>28</sup> Carers Australia (2004), *Fact Sheet*, p. 3 [www.carersaustralia.com.au](http://www.carersaustralia.com.au).

<sup>29</sup> Carers Australia (2004), *Fact Sheet*, p. 3 [www.carersaustralia.com.au](http://www.carersaustralia.com.au).

<sup>30</sup> Deakin University and Australian Unity Limited (2007), Australian Unity Wellbeing Index, Survey 17.1, Special Report: *The Well-being of Australians – Carer Health and Well-being*, October 2007.



section provides details about the three critical areas of policy relevant to enabling carers to balance their work and caring responsibilities for the aged and/or people with a disability, namely (i) financial support; (ii) service provision; and (iii) workplace policies.

### **(i) Financial support**

In terms of financial policies, TOCC reviewed the suite of Australian benefits and allowances as described in Annexure 1. As the key financial supports for carers are the Carer Payment and Carer Allowance, these are discussed here in more detail.

The Carer Payment provides income support to people who, because of the demands of their caring role, are unable to support themselves through substantial workforce participation. The Carer Payment is both income and asset tested. The maximum fortnightly rate of Carer Payment, is \$525.10 for singles, and \$438.50 for each member of a couple. Under the income test, singles can earn up to \$132.00 per fortnight and remain eligible for the full Carer Payment. Singles who earn more than \$132.00 but less than \$1459.25 per fortnight may be eligible for part-payment.

The Carer Allowance is not income or asset-tested and may be paid on top of wages, Carer Payment, or other payments, such as the Age Pension. The Carer Allowance is a non-taxable fortnightly payment of \$98.50.

The Standing Committee reported that the Commonwealth spends \$1.3 billion per annum on the Carer Payment and \$1 billion on the Carer Allowance.<sup>31</sup> However, these payments only provide about half the estimated lost opportunity cost to carers for income foregone, which in 2005 was valued at \$4.6 billion<sup>32</sup>, and in no way covers the replacement cost of the care that they provide, which was valued at \$30.5 billion<sup>33</sup>.

While the Carer Payment allows carers to work up to 25 hours per week (including work study, training or volunteer work) its structure works against maximising workforce participation. By establishing a maximum hours limit a carer can work before the Carer Payment reduces and without recognising potential increased cost for quality appropriate alternate care arrangements, the structure encourages carers to minimise labour force participation.

The need to provide a structure that encourages carers to increase their labour force participation, without placing an undue burden on the public purse, led TOCC to recommend that

*The Government introduce a 50% Care Cost Reimbursement for employees with caring responsibilities (for children, the elderly and people with a disability) to be capped at a net amount of \$10,000 of the out of pocket expense per household per annum.<sup>34</sup>*

<sup>31</sup> House of Representatives, Standing Committee on Family and Human Services, Balancing Work and Family, Report on the inquiry into balancing work and family, December 2006, p. 277.

<sup>32</sup> Access Economics (2005) *The Economic Value of Informal Care*, August 2005, p.12.

<sup>33</sup> Access Economics (2005) *The Economic Value of Informal Care*, August 2005, p. 15.

<sup>34</sup> TOCC (2006) *Where to now? 2006 TOCC Final Report*, p. 6.



The Standing Committee noted that expenses for care are classified as private expenses but particularly with many women participating in the workforce, the bar and the tax deductibility of these expenses was "indefensible"<sup>35</sup>. This resulted in their recommendation that carers:

*(H)ave the choice of either receiving all current carers' benefits or claiming these costs as a tax deduction where they can demonstrate that paid care was necessary to allow them to work<sup>36</sup>.*

Whilst the proposed solutions of TOCC and the Standing Committee are different, both groups agree that the current carer benefit structure inadequately meets increased care costs arising from carers increased labour force participation.

While both pieces of research were known and available to Government, along with similar submissions from groups such as Carers Australia, prior to the Budget 2007-08, the response from Government was to provide for a one-off \$1000 bonus for recipients of the Carer Payment and \$600 to recipients of the Carer Allowance.

In its Federal Budget Analysis, Carers Australia, in respect of the one-off payments announced in the 2007-08 Federal Budget, commented:

*This is the fourth time these bonuses have been paid. These were not indexed, legislation was not proposed so they become annual, nor was the Carer Payment bonus extended to other carers who receive related Centrelink support. Less than 400,000 people will qualify for these Carer Bonuses, leaving 2.2 million carers with nothing.<sup>37</sup>*

While TOCC is supportive of any increased funding to carers to reduce the current high cost of care, TOCC, together with Carers Australia, has been critical of the model of funding as well as the level. In terms of the model, the funding appears to be more in the way of welfare, than a strategy linked to enhancing workforce participation choices, and increases have been by way of a "top up" to a bonus structure. In terms of the level, providing carers with an additional \$11 to \$19 per week will not significantly reduce the high cost of care.

In TOCC's view, whilst Australian carers are provided with a minimal level of financial support to compensate them for their caring activities, the current system demonstrably fails to meet carer needs to pay for replacement care, and therefore workforce needs for skilled labour. As will be demonstrated in chapter 3 ("Facts and figures"), the cost of care is particularly acute for carers of people with a disability. Further TOCC suggests that the appropriateness of the underlying model of financial support has been called into question, and that it is time for new thinking about options for reform via a comprehensive review.

<sup>35</sup> House of Representatives, Standing Committee on Family and Human Services, Balancing Work and Family, Report on the inquiry into balancing work and family, Dec 2006, p. 282.

<sup>36</sup> House of Representatives, Standing Committee on Family and Human Services, Balancing Work and Family, Report on the inquiry into balancing work and family, Dec 2006, p. 282.

<sup>37</sup> Carers Australia (2007) *Federal Budget 2007-2008 Analysis*, [www.carersaustralia.com.au](http://www.carersaustralia.com.au)





### **(ii) Service provision**

In relation to recent initiatives to support carers for the aged, the Commonwealth Government has supported Employed Carer Innovative Projects (ECIPS) as a strategy to increase service provision. These projects aim to provide working carers of the frail aged with more opportunities and flexibility to combine caring with work, training or study. Due to the cross portfolio nature of some of the projects an interdepartmental reference group was established, comprising the Department of Health and Ageing (DoHA), the Department of Employment and Workplace Relations (DEWR), the Department of Education, Science and Training (DEST), the Department of Family and Community Services and Indigenous Affairs (FACSIA), the Office for Women, the Department of Veterans Affairs (DVA) and Carers Australia. This reference group provides input and expert advice on development, implementation and evaluation of the ECIPS. A summary of the projects is included in Annexure 2, together with detailed feedback from each of the project co-ordinators where available.

There were originally 21 projects identified as possible ECIPS and these were offered seed funding to develop their proposals more comprehensively. To date there are 16 projects underway with a further two possibly to start in the future.

These projects are encouraging, looking at a range of issues including the investigation of respite care to assist employed carers, seniors daycare, fee structure and flexible work practices. However, the number of projects is small in number relative to the number of carers, and the impact confined to a local community. The projects also exclude employed carers of people with a disability, chronic conditions or mental illness. Further, there is no apparent re-current funding once the innovative project funding ceases at the end of June 2008.

In relation to carers of people with a disability, under the recently announced Disability Assistance Package the Commonwealth Government will provide \$23.6 million over five years for a small number of children's disability services where other support options are limited<sup>38</sup>. These services are still to be implemented, but could provide vacation and out of school hours care, as well as out-of-home care for children so that their parents can have a break or continue in the workforce. The package will provide funding certainty for around 20 existing specialist services for children with disability and provide for a small number of additional services targeted to areas of high need.

Finally, as indicated in chapter 4 of this report ("The voices of formal and informal carers"), whilst current Government strategies to improve the work/care dynamic are valued by carers, there is concern that the services are (overall) fractured, difficult to access, and insufficient. The sufficiency of these services has a direct impact on carers' ability to access formal care during periods when they are at work.

### **(iii) Workplace policies**

Through workplace related legislation, such as the *Sex Discrimination Act 1984* (in relation to family responsibilities) plus anti-discrimination legislation enacted

<sup>38</sup> Minister for Families, Community Services and Indigenous Affairs, *Huge increase in Howard Government funding for People with Disability and their Families*, Media Release, 28 June 2007.



by the States/Territories, there is some level of protection for employees with caring responsibilities<sup>39</sup>. Annexure 3 provides a comprehensive summary of relevant legislation in relation to work and caring responsibilities.

Whilst there is some inconsistency between Federal and State legislation, taken at its highest, anti-discrimination legislation prohibits direct and indirect discrimination in employment on the basis of a person's caring responsibilities, and further requires an employer to make reasonable accommodations for people with caring responsibilities, eg by implementing flexible work practices.

The question is whether this legislative framework provides (i) sufficient (and consistent) impetus for employers to implement work policies which are supportive of carers; and (ii) appropriate guidance on negotiating those arrangements to meet both personal and business needs. In this regard TOCC observes that relevant Federal anti-discrimination legislation has fallen behind advances in State legislation. In particular the ambit of protection for employees with caring responsibilities is now narrower under the *Sex Discrimination Act 1984 Act* (Cth) than under comparative State legislation, eg the *Anti-Discrimination Act 1977* (NSW). This leaves both employees and employers unclear about their rights and obligations.

Further, following a review of Federal anti-discrimination law, the Human Rights and Equal Opportunity Commission concluded

*Current federal anti-discrimination law provides insufficient protection for men and women with family and carer responsibilities, and a limited platform to support and promote systemic change.*<sup>40</sup>

In particular Australian workplace legislation does not provide a right for employees to request flexible work practices to accommodate their caring responsibilities, nor compel employers to report on strategies they have developed and implemented to assist carers (similar to the reporting model used in relation to gender equity under the *Equal Opportunity for Women in the Workplace Agency Act 1999* (Cth).

The need for workplace reforms to assist working carers and employers has been recognised by both carer groups (eg Carers Australia) and employers (the Business Council of Australia). In a Federal Budget Submission 2007-08, Carers Australia suggested that the Federal Government introduce legislation to provide carers with the right to flexible working hours; the establishment of an Employers for Carers Programme which would provide financial incentives to employers to participate; plus a national carers' gateway (similar to that established by the Disability and Aged information Service in New South Wales) which would provide information to carers and employers and carer-friendly workplaces<sup>41</sup>. The Business Council of Australia has recommended the establishment of a working party to address current barriers to workforce participation, including those experienced by carers. In particular the BCA has recommended the

<sup>39</sup> Details of the legislation are summarised in Annexure 3.

<sup>40</sup> Human Rights and Equal Opportunity Commission (2007), *It's About Time: women, men, work and family*, [http://www.hreoc.gov.au/sex\\_discrimination/its\\_about\\_time/index.html](http://www.hreoc.gov.au/sex_discrimination/its_about_time/index.html), p 57.

<sup>41</sup> Carers Australia (2007) *Federal Budget 2007-08 Analysis*, pp 4-5



initiation of a “defined project” and the establishment of a “working group consisting of government, not-for-profits and business” to undertake this work. The BCA suggested that one of the outcomes of the project could be the development of a “Workplace Diversity Kit for businesses which highlights the need for and benefits of greater diversity in the workplace”<sup>42</sup>.

Finally, the need for legislative reform has been endorsed by the Human Rights and Equal Opportunity Commission. The shape of these reforms was explored in HREOC’s 2007 report *It’s About Time: women, men, work and family*, a centre piece of which was a recommendation for the Federal Government to enact a Family Responsibilities and Carers’ Rights Act. This Act would include “a right for workers with family and carer responsibilities to request flexible arrangements with a corresponding duty on employers to reasonably consider those requests” and “provide protection from discrimination for employees with family and carers responsibilities”.<sup>43</sup> HREOC also recommended an extension to carer leave entitlements. To date the Federal Government has not implemented, nor committed to implement, HREOC’s recommendations for legislative reform.

TOCC’s supports the recommendations of the BCA in relation to the development of tools to raise employers’ awareness of the benefits of workplace diversity (including work/caring), as well as the recommendations of HREOC in relation to the introduction of a Family Responsibilities and Carers’ Rights Act.

How else might public and workplace policies be further enhanced? In order to identify best practice, TOCC investigated strategies employed by comparative jurisdictions, and in particular the United Kingdom.

#### **2.4 Looking afield for best practice solutions**

TOCC investigated legislative and financial policy initiatives in comparative jurisdictions, including Canada, Japan, The Netherlands, New Zealand and the United Kingdom. A summary of those provisions is attached at Annexure 4. Given the best practice nature of recent reforms in the United Kingdom, and the relative ease with which they might be transferred to the Australian context in light of jurisdictional similarities, this section focuses on the UK experience.

As at 2001 the British Census recorded there were 3 million people in Britain combining work and caring responsibilities<sup>44</sup>. To assist carers to balance these responsibilities, in 2002 the British Government introduced legislation which provides parents of children under six, or under 16 if the child has a disability, a right to request flexible work practices. In 2006 this right was expanded to include carers of adults via the *Work and Families Act 2006*<sup>45</sup>. While the legislation does not provide an absolute right to flexible work arrangements, an employer who receives a request must give it serious consideration.

<sup>42</sup> Business Council of Australia (2007) *Employing Our Potential: Ensuring Prosperity Through Participation*, Workforce Participation Roundtable Discussion Paper, p. 32.

<sup>43</sup> HREOC (2007) *ibid* p 59, 64.

<sup>44</sup> Ace National Action for Carers and Employment, *Who Cares Wins: The Social and Business Benefits of Supporting Working Carers*, p. 2.

<sup>45</sup> Carers UK (2006), *New Right to Request Flexible Working for Carers of Adults*, [www.carers.org](http://www.carers.org)



In addition to these legislative provisions, the British Government (via Government websites<sup>46</sup>) and Carers UK<sup>47</sup> provide information about flexible work practices to carers and employees, including forms and letter templates associated with the request process<sup>48</sup>. Carers UK also works with major employers to help implement flexible work practices for employees with caring responsibilities through a partnership called Employers for Carers.<sup>49</sup>

In terms of outcomes, the (UK) Third Work-Life Balance Employer Survey (released in November 2007) found that the legislation has garnered support from both employers and employees. In particular the report found that

*(T)he availability and take-up of work-life balance arrangements has increased since 2003, with two or more flexible working time arrangements being taken up by employees in over four in ten workplaces. The vast majority (92 per cent) of employers reported that they would consider a request to change a working pattern from any employee, despite legislation only requiring employers to do so for some employees. Amongst those employers where a request had been made in the previous 12 months, just nine per cent said they had turned down any requests.*

In relation to employer responses the report found that

*Employers continue to hold predominantly positive attitudes towards work-life balance and to perceive its benefits for employees and workplaces alike, although it is clear that most employers feel that the implementation of flexible working practices is not always easy, and should not be expected by employees where it would cause disruption to the business.<sup>50</sup>*

On 3 September 2007 the British Prime Minister announced the establishment of a Standing Committee on Carers, which reports to the Secretary of State for Health. The Committee provides a voice for carers in central policy creation, looking at both long and short term “including developing the Prime Minister's New Deal for Carers and responding to the fundamental challenges of an aging society, people choosing to receive care in their own homes, changing family structures and the need to reorganise the care system so more control is in the hands of those who use services and their carers”.<sup>51</sup> The Committee, which includes representatives of carer groups, is a different structure to the Standing Committee on Family and Human Services in Australia, which is made up of parliamentary members, and shows an intent of the British Government to deal with matters relating to carers using a more inclusive approach.

<sup>46</sup> [www.direct.gov.uk/Employment/Employees/fs/en](http://www.direct.gov.uk/Employment/Employees/fs/en) and [www.businesslink.gov.uk/bdotg/action](http://www.businesslink.gov.uk/bdotg/action)

<sup>47</sup> [www.carers.org](http://www.carers.org)

<sup>48</sup> Carers UK (2006), *New Right to Request Flexible Working for Carers of Adults*, [www.carers.org](http://www.carers.org)

<sup>49</sup> [www.carers.org](http://www.carers.org)

<sup>50</sup> Department for Business, Enterprise and Regulatory Reform (2007) *The Third Work-Life Balance Employer Survey, Executive Summary*, Employment Relations Research Series (No. 86), November 2007. <http://www.berr.gov.uk/files/file42220.pdf>.

<sup>51</sup> Department of Health (National), *Terms of reference for the Standing Commission on Carers*, Media Release 3 September 2007



The UK's legislative response to the needs of employed carers, the resourcing of the promotion of flexible work practices, the partnership between government, employers' and carers' associations and the establishment of a standing committee demonstrate a strategic and best practice approach to supporting working carers. TOCC is of the view that the Australian Government's adoption of similar policy and legislative initiatives would be of significant value to Australian carers and employers.

## **2.5 Summary**

This introductory chapter has described the factors which are impacting the work/care dynamic and has observed that Australia is currently experiencing a dual pressure for increased labour force participation and the provision of informal care. TOCC has suggested that there are clear indicators that these dual pressures are not being managed effectively, namely the (involuntary) under-representation of carers in the labour force, carers' lower sense of personal well-being, and carers' economic disadvantage. In summary, current financial supports, workplace policies and services are ready for improvement to enable better outcomes for carers and employers, and therefore the broader economy.

Finally, TOCC has identified the need for legislative reform to enable employees to better balance their work and caring responsibilities through flexible work practices. In this regard TOCC supports HREOC's recommended implementation of a Family Responsibilities and Carers' Rights Act, as well as the strategic approach to change demonstrated by the UK Government.



### 3. Facts and figures

In 2007 TOCC conducted a random sample national survey of 2,284 Australians aged 18 years and over who work full or part-time.<sup>52</sup> Of that sample, 383 self-identified as currently providing care for a person who is aged and/or has a disability or a chronic health condition. These respondents were asked a series of questions about the work/care dynamic and options for improvement.

In addition, from a total sample of 1901 respondents, 507 self-identified as expecting to provide care in the next five years for a person who is aged and/or has a disability or a chronic health condition. These respondents were asked questions about their preferred workplace strategies to manage these expected responsibilities.

#### 3.1 Employees who currently provide care

The three main areas covered in this part of the survey concerned (i) the relationship between work and the cost of care; (ii) the impact of care on jobs/careers; and (iii) the initiatives that would most assist carers to balance work and care.

##### (i) The impact of the cost of care on workforce participation

Respondents confirmed the results from previous TOCC surveys in 2004 and 2006, namely that there is a direct relationship between work and the cost of care. In particular 14% of respondents have considered leaving the workforce because of the cost of care. This outcome is more acute for those caring for a person with a disability/chronic health condition (19%) than with elder care (11%), suggesting that the cost of care is higher for those with disability/chronic health care responsibilities.

Further, 1 in 4 (ie 24%) of carers have already reduced their work hours because of the cost of care, and this outcome applies equally to carers of the aged (23%) and to carers of people with a disability/chronic health condition (25%). Given comments in chapter two on the skill shortage, it is of note that this outcome is more likely to occur for university educated carers (28%) than high school educated (20%).

##### (ii) The impact of care on jobs/careers

The data clearly show the perceived negative impact of caring responsibilities on jobs/careers, and in particular the hidden loss of skills. 1 in 3 (34%) of carers are of the view that their career has suffered because of the competing demands of their caring responsibilities. This perception is particularly acute (43%) for carers of those with a disability/chronic health condition, perhaps reflecting the magnitude and longevity of their caring responsibilities and therefore the demands on their time and energy (as well as finances as described above).

Critically in terms of using the full skill base of working carers, two-thirds (67%) of carers indicated that they would refuse a job or promotion if it meant they could not fulfil their caring responsibilities. Further nearly half (44%) have already

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<sup>52</sup> The survey was designed by TOCC, in consultation with Newspoll, and administered by Newspoll by telephone over the period 12-14 and 19-25 October 2007. Dr Graeme Russell (Partner at Aequus Partners) in consultation with TOCC.

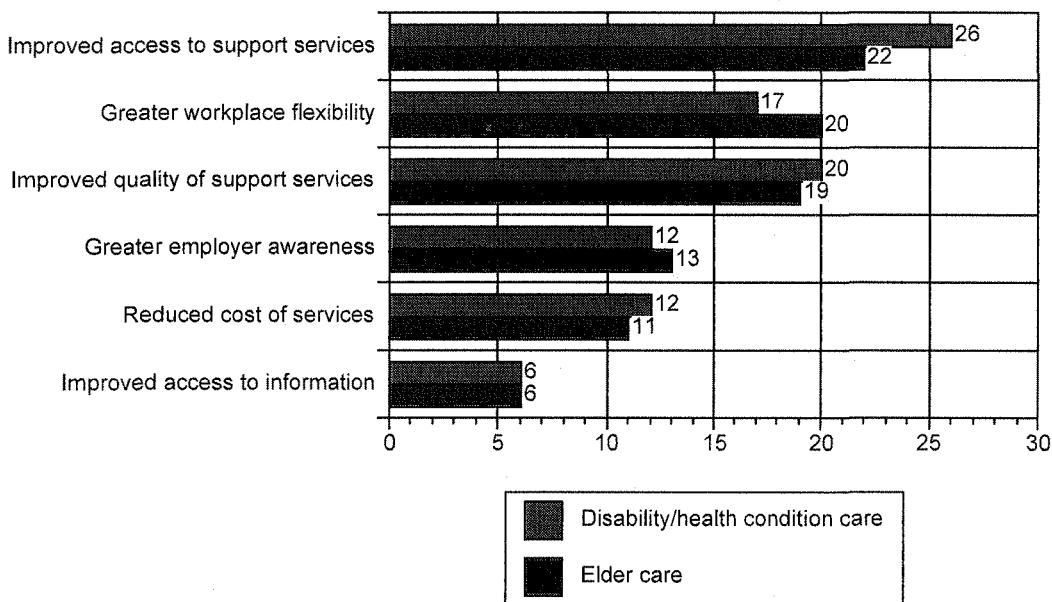


selected a role at work which is below their skill level because it gives them the flexibility they need to balance their work and caring responsibilities.

**(iii) Initiatives that would most assist carers to balance work and care**

The two preliminary focus groups with carers (described in chapter 4, “The voices of formal and informal carers”) identified a range of possible initiatives that would assist carers to balance their work and caring responsibilities. These initiatives included (i) improved access to services; (ii) improved quality of services; (iii) reduced cost of services; (iv) greater workplace flexibility; (v) improved access to information; and (vi) greater awareness of the needs of carers among employers. In order to identify the priority areas for reform, survey respondents were asked to identify the initiative that would *most* assist them to balance their work and caring responsibilities.

The responses are summarised in the graph below. As can be seen (i) improved access to services; (ii) improved quality of services; and (iii) greater workplace flexibility are the three highest priorities for carers of both the aged as well as those who care for a person with a disability/chronic health condition. In terms of aggregate data, improved access to services accounted for 23% of responses, greater workplace flexibility 20% of responses, and improved quality of services 18% of responses.



**3.2 Employees who expect to provide care in the next 5 years**

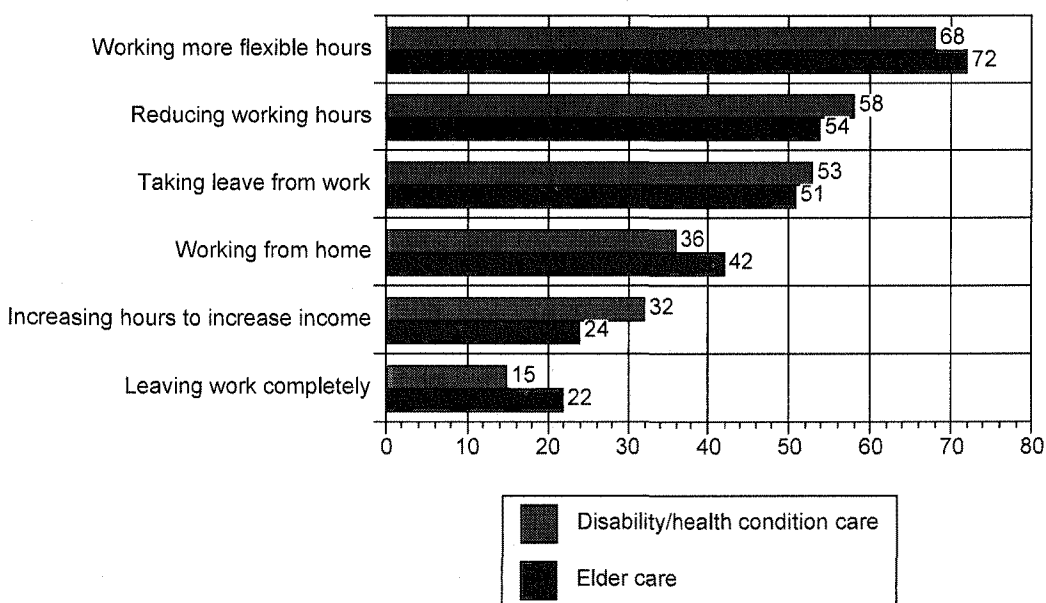
1 in 4 (26%) of the survey respondents expects to provide care in the next five years to an elderly person and/or someone with a disability/chronic health condition. Not unexpectedly, given the ageing demographic, 23% expected to provide elder care, and 6% disability related care.

Whilst there is an obvious gap between projected care and the actual take up of care, expectations of care inform employee choices about their current and future employment prospects. As preliminary focus group participants indicated that workplace flexibility is a key strategy which they currently use to manage their



caring responsibilities, survey respondents were asked about how they would like to manage these responsibilities in terms of the following options (i) reducing hours; (ii) working from home; (iii) taking leave from work; (iv) leaving work completely; (v) working more flexible hours; and (vi) increasing hours in order to increase income. Confirmation that these were the most relevant options is confirmed by only 5% of respondents choosing option seven, namely "none, don't know".

The responses are summarised in the graph below. As can be seen (i) working more flexible hours; (ii) reducing work hours; and (iii) taking a period of leave are the top three preferred strategies for managing work and care. In terms of aggregate data, working more flexible hours accounted for 70% of responses, reducing work hours 54% of responses, taking leave from work 50% of responses, and working from home 41% of responses. These expectations contrast with the findings from the focus groups (discussed in chapter four), namely that carers have found it difficult to access flexible work practices to accommodate their caring responsibilities, particularly if the nature of the arrangement was something other than part-time hours.



### 3.3 Summary

Drawing on TOCC's random sample national survey of working Australians aged 18+, this chapter has provided facts and figures on the work/care dynamic in relation to aged and disability care. In particular the data indicate that

1. There is a direct relationship between work and the high cost of care, particularly for carers of people with a disability/chronic health condition.
2. Carers experience difficulties balancing their work and caring responsibilities, and accordingly chose jobs that are below their skill level in order to obtain a level of flexibility.
3. Enhanced access and quality of services, together with workplace flexibility would most assist carers to balance work and care.





4. Balancing work and care is an issue for now and the future, with high levels of projected aged care.



#### 4. The voices of formal and informal carers

This section reports on the qualitative research conducted by TOCC on the work/care dynamic as experienced by informal and formal carers. In particular this section reports on the (i) aim; (ii) methodology (including sampling details); and (iii) key findings of the research.

##### 4.1 Aim

The aim of the research was to:

1. understand the qualitative experience of carers balancing paid work and caring for the aged and/or a person with a disability;
2. Identify the broad range of options for reforms by Governments and employers to enhance the work/care balance;
3. identify priority areas for change.

##### 4.2 Method

The methodology for the research comprised three data collection phases, administered by Families Australia<sup>53</sup>, namely:

- two preliminary focus groups held in Sydney<sup>54</sup> (at the Insurance Australia Group office) and Melbourne (at the National Bank office) on 26 and 27 September 2007. In addition to questions aimed at understanding the qualitative experience of carers, and options for reform<sup>55</sup>, a key aim of these focus groups was to test the draft questions to be included in a random sample Newspoll survey slated for 13 and 14 October 2007,
- an Expert Roundtable Meeting in Canberra on 5 October 2007, which involved representatives of the following peak national not-for-profit organisations: Alzheimers Australia, Anglicare Australia, Arthritis Australia, Australian Nursing Federation, Carers Australia, Deafness Forum Limited, Families Australia, Family Relationship Services Australia and Palliative Care Australia, and
- three follow-up focus groups held in Sydney (17 October 2007), Melbourne (18 October 2007) and Wollongong (29 October 2007). A key aim of these focus groups was to interpret data obtained in one of three Newspoll surveys conducted, and to more comprehensively explore priority areas for reform.

##### 4.2.1 Sampling details

In all, 58 people participated in the five focus groups. *Appendix A* contains an analysis of demographic information about focus group participants. The salient points are that, of the total number of participants:

- 69% were female and 31% were male;

<sup>53</sup> Families Australia's focus group methodology is based on Australian and overseas best practice and is supported by a quality assurance framework. The following report should not be taken to represent the views of any particular participant or participants, nor the consensus of the focus groups and other consultations.

<sup>54</sup> On behalf of TOCC, the Sydney focus groups (both preliminary and follow-up) were hosted by the Insurance Australia Group, and the Melbourne focus groups (both preliminary and follow-up) were hosted by the National Australia Bank. The Expert Roundtable was hosted by Carers Australia in Canberra.

<sup>55</sup> The specific questions asked of focus group and roundtable participants were: (i) What is your experience concerning the capacity of carers to balance work and aged/disability care?; (ii) What can employers and governments do to enhance Australian's choices about balancing work and aged/disability care? (What are the key elements of a workplace and community environment that would allow Australians to balance work and care more effectively?); and (iii) What are the priority areas for change?



- 65% worked full-time, 28% worked part-time and 5% were not in paid employment;
- 64% were aged over 45 years;
- 14% had household incomes of less than \$50,000 per annum; 45% had household incomes of between \$50,000 and \$125,000 per annum, and 33% had household incomes over \$125,000 per annum;
- 28% were single and 60% were living with a partner;
- 74% had children, of which 79% had two or more children;
- 64% cared for one or more people, of which 41% cared for two or more people;
- 64% of those who cared for one person did so in respect of an aged person, while 27% did so in respect of a person with a disability; and
- 46% of those in caring roles provided between 5 and 20 hours care per week and 35% provided greater than 23 hours care per week.

### 4.3 Findings

For ease of reference, comments by focus group and expert roundtable participants are arranged according to the three questions asked of participants, namely relating to (i) experience; (ii) broad options for change; and (iii) priority areas for change.<sup>56</sup> Key findings are summarised at the end of each section 1.3.1 in relation to the experience of carers; and 1.3.3 in relation to priority areas for change.

#### **4.3.1 Understanding the experience of carers balancing work and care for the aged and/or a person with a disability**

Participants highlighted a broad range of experiences in balancing work and caring roles. The major themes concerned (i) the workplace; (ii) service access/provision; and (iii) the personal/community impact. Comments are summarised in relation to each theme, and some verbatim comments included at the end of each sub-section

##### (i) The workplace

- Positively, some workplaces, particularly large national firms, have employment policies and practices which seek to provide greater work flexibility for those who have caring responsibilities.
- There appears to be a wide degree of variability, however, in policies and practices between employers. There can also be wide variations in practices at the level of the work unit within an organisation, with some managers being more supportive than others.
- Sometimes, the level of an individual manager's support or understanding of employee caring responsibilities is not clearly informed by broader organisational policies.
- Many participants wished for more flexible working hours, including employment on a genuine part-time basis (that is, without it becoming a de

<sup>56</sup> This report is provided with the caveat that Families Australia's examination is based mainly on face-to-face meetings with groups and individuals. Except where quantitative data as derived and referenced from other sources is cited, the primary source of information is qualitative; as such, it is necessarily limited due to the restricted number of participants and locations in which consultations occurred. As with all Families Australia qualitative research, this report carries the caveat that additional consultations are required to provide relatively greater assurance as to the general application of the findings.



facto full time job) and greater opportunities to work from home with greater utilisation of the Internet. Some participants felt that employers did not trust employees to work distant from the office.

- Many participants perceived that the demands placed on them as a result of their caring roles were often or sometimes not well understood by their work colleagues. This can breed resentments.
- There was strong and widespread concern about the lack of adequate paid or unpaid leave for caring roles beyond carer leave entitlements that exist for some employees.

Verbatim comments made by participants in relation to the workplace included:

*I have a daughter with autism and I work full-time. My wife was a highly paid, successful journalist. My law firm is very progressive for women, but men are not encouraged or rewarded for taking the interests of their family seriously. I have gone to a nine day fortnight but I would like to split care more evenly. Corporate Australia does not understand that life is not neat. The character of [your manager] makes a huge difference. (Focus group participant)*

*My work is very supportive and allows me flexibility as my situation is not static. I could disappear, take work with me and plug in anywhere. My manager had his own caring experience and understood my needs and helped to manage it. (Focus group participant)*

*I'm looking at 20-30 years of care for my daughter – it's too distressing to plan that far ahead. Having a supportive manager made all the difference. My company doesn't care where or when [my job gets done] as long as it gets done. It would be nice if this was a more consistent attitude [within organisations]. (Focus group participant)*

*I asked [my employer] for a nine day fortnight. It was no problem. But there's inconsistency between employers. The outcomes shouldn't depend on the individual manager. (Focus group participant)*

*Co-workers don't understand. You should be able to take them home with you; then they'll stop thinking you're scamming. Perhaps produce some films or ads, showing the real life stuff of caring. (Focus group participant)*

*There's a real resistance from employers to embrace working from home. With technology, it's quite possible for people to contribute more to the workforce by having the capacity to be able to work at home, and we're finding employers very reluctant because of occupational health and safety and insurance considerations and fear that people don't give or won't be as productive as they would if they've got them under their eye all the time. We need an attitudinal shift. (Focus group participant)*

*Things that have been traded away in the new workplace relations system are things that don't seem to be valued by employers but which we've fought for, such as carer's leave and bereavement leave. (Focus group participant)*



*One of the things in the workplace where there is the most difficulty, stress and conflict is with people who are in transition from caring and still trying to work full-time. Once they've reached the point where they realise they can't, the issue is then trying to negotiate some agreement so it facilitates their caring responsibilities. (Focus group participant).*

(ii) Service access/provision

- There was broad concern about the difficulty carers faced in understanding how to access information and assistance from governments, for example, in finding where to obtain in-home and out-of-home care tailored to specific requirements or conditions. The task of knowing what assistance might be available appeared to have been made particularly complex by the division of caring support between various levels of Australian governments and between various non-government agencies.
- Several participants referred to the difficulty they faced in accessing before-school, after-school and vacation care, especially for children with a disability.
- Concern was also expressed about the lack of respite for carers, particularly in non-metropolitan and rural areas.
- Many participants felt that there was a far higher load in caring for family members with a disability compared with the care required for ageing family members; this related mainly to the unpredictability and need for constant supervision of many persons with a serious disabilities. Many participants considered that it is important for policy thinking and support programme delivery to carefully take this distinction into account.

Verbatim comments made by participants in relation to the service provision included:

*My father has diabetes. A nurse came in two days a week for 12-15 months; then they trusted him to continue the routine himself. That was good – but you have to know the service is available. (Focus group participant)*

*[Comparing the caring needs of children and ageing people] we know our grand-children will be with us for 18 years at least. With ageing parents, you have no idea how long they'll be around. What if they live on beyond your career break, and you have to quit, and you're in your late 50s trying to get back into the workforce? (Focus group participant)*

*There's only one respite carer in [the participant's large regional city] who can deal with high needs children and who has wheelchair access to their house. (Focus group participant)*

*None of the specialist or government-run disability schools has before-school care, or after-school care, or vacation care. (Focus group participant)*

*Elderly respite care is inadequate. There are not enough placements. (Focus group participant)*



*When my [non-English speaking background] father's neighbours died, my father became very isolated. We found a [language specific] support group where someone drops in on him and takes him shopping, and a centre, where he goes once a week. As he's also deaf, he needs that [communication and stimulus]. It's a load off my mind. (Focus group participant)*

*Care costs. I scrimped and saved. I had to find \$60 a month for a cleaner, for instance. I used the carer allowance for taxis and hearing aids for my father, home care and maintenance. (Focus group participant)*

*If you have someone who is disabled it's not a matter of whether you can afford care – it's whether you can find it, because there just isn't the places that you can get care. There are not enough places and there are not enough quality carers out there to do the job. (Focus group participant)*

*The general population probably has more empathy for people who have aged care responsibilities because they all have an elderly relative or they know somebody who is elderly. However, in the case of carers of those who have disabilities, there is much less awareness of what that involves and what their needs are. (Focus group participant).*

(iii) The personal/community impact

- There was concern that caring roles frequently resulted in a person being forced to leave the workforce, or undertaking part-time work or refusing to take promotion or having to take extended unpaid leave.
- Many noted that a significant disincentive to leave the workforce to provide care was the adverse effect on the person's superannuation and levels of satisfaction and wellbeing in later life.
- Many participants considered that they needed to stay in the workforce in order to pay the high costs associated with care, yet this meant that getting a satisfactory work-life balance was difficult, and stress levels were often unsustainably high. There was also concern about the unequal burden placed on non-working partners.
- Several noted that the relationship breakdown rate within families where a family member had high care requirements was far higher than for other types of families.

Verbatim comments made by participants in relation to the personal/community impacts included:

*My son has autism and a mental disability. I became a sole parent. I had to make a career choice: less pay, less responsibility in order to cope with the demands. I can't now handle a high pressure job managing lots of staff. It's a full-time job trying to access opportunities for my child. In terms of GDP, the cost of having carers unemployed and not contributing financially is creating burdens later on [for society and the individuals concerned]. (Focus group participant)*



*When my stepfather [in a regional city] is no longer able to live at home, I won't be able to care for him. He has a brain tumour and is mentally disabled. As he gets worse, he'll need professional help. (Focus group participant)*

*Sometimes you're doubly disadvantaged – even triply. You're caring for someone with a disability or frail and aged, you're not working which means you're in that poverty cycle and often, especially with kids with disabilities, the rate of marriage breakdown is about 90 percent. (Focus group participant)*

*Most people want support - not to be carried – to stay in the workforce. I felt I was being penalised for having a daughter with a disability. I was forced out of the workforce into poverty. There is no childcare for children with autism; the boss doesn't understand that. You need income, superannuation, investment for the future. The relationship break-up rate is huge. (Focus group participant)*

*I keep seeing women forced out of the workforce, living in poverty. Explaining to others is hard. It's limiting for the kids – they don't get into sports teams and have no birthday parties. It's hard work caring and enriching kid's lives. You have to source your own information. It's like a second job which is huge and hidden. (Focus group participant)*

*Since my daughter was injured [twenty years ago], I have refused promotions because I knew that I'd be expected to travel interstate and to work longer hours. I've had to drop levels and take less and less responsibility. I've had problems with managers who say I'm not doing the work – because I can't go interstate or work till 7pm. (Focus group participant).*

In summary, the key findings in relation to the experiences of carers balancing work and care are:

#### **4.3.2 What needs to change to enable carers to better balance work and care?**

Participants made a wide range of suggestions for improving the situation for carers of people with a disability and/or the aged to enable a greater balance between work and care. The main themes concerned (i) the workplace; (ii) Government policy; and (iii) service provision. The following section will identify priority areas for change:

##### **(i) The workplace**

- **Flexible work practices:** Many participants felt that employers should offer a greater range of flexible workplace arrangements, such as part-time leave and the conversion of sick leave entitlements to a carer's entitlement. Further there is a need for enhanced consistency in employer care policies and practices both within and across organisations.
- **Information:** Information about various types of care assistance should be made clearer and more accessible to current and prospective carers and their employers. Further employers should be assisted by governments in



finding out about available, accessible and quality services in order to make information available to employees about support services.

- *Education:* There should be greater education for the co-workers of persons who are in caring roles.

Verbatim comments made by participants in relation to the potential workplace reforms included:

*Internal [workplace] websites can make information more accessible. If it's clear upfront, it's easier for lower level managers. List the [care] options and make it clear. (Focus group participant)*

*We need a DVD on 'a day in the life of a carer' to show my work mates so they'll understand I'm not just taking time off for no reason. (Focus group participant)*

*There needs to be acknowledgement amongst employers that people do have caring responsibilities and they need to be flexible in employment policies. (Focus group participant)*

*The Employee Assistance Programme could link in to support services and groups and refer people when they present with caring issues. (Focus group participant)*

*There is too much randomness and arbitrariness within organisations [in relation to flexible work practices for carers]. While I have very supportive people where I work, I hear of plenty of people who don't have that support. There almost needs to be a national charter that has the agreement of Federal Government and organisations. (Focus group participant)*

*I would like to see that volunteerism and caring is something every workplace provides for so I can go on leave if someone's dying and keep my job going or at least keep my wages going. I need more time-out and for that to be a universal standard that is recognised by all employers. (Roundtable expert)*

*Education of employers, not necessarily just of a particular condition, whether it be dementia or whether it be arthritis, the problems of those that need to care and the benefits of supporting those carers in the workplace is where we need to focus. (Roundtable expert).*

(ii) Government policy

- *Financial policy:* Participants uniformly called for far greater government financial support and other resources to be provided to carers. There were strong calls for more accessible and higher quality services in areas of need.
- *Legislative framework:* Some participants suggested that the Government should introduce legislation that would establish principles and guidance for government, employers, employees and community organisations in relation to the implementation of family friendly workplaces.





Verbatim comments made by participants in relation to potential policy reforms included:

*We need a joined-up approach in workplace policy and service provision. Caring needs to be recognised as a social duty. (Focus group participant)*

*We need a 'Tool Kit for Caring'. (Focus group participant)*

*For people who choose to go down to part-time it would be really terrific if the government then gave the part-time allocation of the carers payment. The payment is income tested and I can line up carers who have never tapped into that support. If you choose to go down part time there should be some way also of having some part-time access. (Focus group participant)*

*I'd be willing to increase the premium of my insurance by \$20 a year to go into some scheme that would help people with long time care costs. (Roundtable expert)*

*I think the idea of a levy is really important because there is a lack of trust. We're happy to be paying more taxes if you invest in more services. [People may be likely to be] willing to pay the tax if the money is dedicated for that purpose. That's one reason why Medicare is so popular - you've got a guarantee that that money is spent on health. (Roundtable expert)*

*I think a quick win could be to get legislation to recognise the validity of caring. So in terms of Newstart or Work for the Dole, voluntary work and caring could be recognised. (Roundtable expert).*

**(iii) Service provision**

- *Navigation:* Many participants expressed concern and even anger at the current fragmented system of support for carers and wished for a 'joined-up', one-stop shop approach instead of the current piecemeal approach. This would entail, for example, a designated central point of contact for carers instead of carers having to contact, often numerous, organisations for help.
- *Uneven resourcing:* Participants from rural and remote areas highlighted the disadvantages they faced compared with metropolitan areas in accessing adequate services, and called for a greater range of services to be provided in those areas.
- *Staffing:* Participants suggested that the quality and longevity of staff would be improved if care workers were paid more competitive wages. Further participants suggested that greater encouragement should be given to people to enter this type of work.
- *Under resourcing:* Many carers of children with a disability called for before-school, after-school and vacation care for a variety of reasons, including that such services would encourage workforce participation.



Verbatim comments made by participants in relation to potential service reforms included:

*Employer support works better if services are there in the first place. I had to use Amazon and search the web. You feel isolated. Government has failed on disability services as the system has become privatised which means that you [the carer] become a full-time [unpaid] case worker. (Focus group participant)*

*There's a need for more education of health professionals. No-one can answer questions. It's hard to make informed choices. (Focus group participant)*

*The path to getting assistance is difficult especially if you don't qualify for assistance. For example, if your child is physically OK [but has a mental disability], how do you get him into a hostel? How do you find care and support? What can the system deliver? (Focus group participant)*

*We need a one-stop shop, pulling together the links in the chain. You need to know the right question to ask to find the next link. Every parent reinvents the wheel. (Focus group participant)*

*There is a dire crisis in the staffing of places like aged care facilities and group homes and the staff are not recognised and they are not paid enough. Give them the qualifications and better pay before it is your turn. (Focus group participant)*

*There needs to be an attitudinal change in terms of [what Government] will provide as respite for working parents and carers. There's a real problem between Federal Government and State Governments, passing the buck to each other so families are stuck in the middle. (Focus group participant)*

*It needs to be not just policies [but] real things so that people in those professions get proper holidays and proper support and do feel that they're doing a great job and being rewarded for doing that. (Focus group participant)*

*We know how many family carers there are, but one of the issues that people have to deal with all the time is the emotional toll of caring and not having enough services in place that are responsive. The home and community care programme was there for older people but [programmes for] people with disabilities and their family carers have never got substantial increases in money. (Roundtable expert)*

*If you can actually get people into a supportive network earlier rather than later, you avoid some of the crisis points, and you probably get better care in the home, you get perhaps earlier access to services at a lower level which might actually help - take it away from the crisis into more the planned response. (Roundtable expert)*



*There is a difference between what happens in rural and in metro areas. The stats show that it's better to die in a small rural community in Australia than in an outer metro area. The criteria that differentiate your experience is that your community is more likely to be around you – knocking on your door, helping your family and supporting you through that process compared to being isolated. Who's actually doing the caring work of that family is the rural community. When it comes down to advocacy, looking at the geographic and demographic issues [would be desirable]. (Roundtable expert)*

*At the population level there is a need to better understand population groups and trends. We have data like ABS data at a very high level but we can't put services in place unless we know what the needs are at a much more fine level. (Roundtable expert).*

#### **4.3.3 What are the priority areas for change?**

The top priorities for change, as identified by carers and roundtable experts in terms of the frequency of comment and level of agreement within respective groups, concern (i) valuing carers; (ii) responsive workplaces; and (iii) public policy:

In summary focus group participants and roundtable experts recommended that:

##### **1. Valuing carers:**

- a. Carers' experiences should be recognised and valued in the workplace to a far greater extent than at present, for example, through awareness raising programmes which are promoted, championed and modelled by senior managers.

##### **2. Responsive workplaces:**

- a. Workplace policies and practices should become increasingly flexible in finding ways to accommodate the varying requirements of carers. Greater effort is needed, for example, to ensure that workplace practices in relation to caring are applied equitably across organisations and managers are supported to implement those policies.
- b. Employers are encouraged to institute services which assist their employees to locate and access caring support services, for example, through connected Intranet databases and designated human resource support in the area of caring.
- c. Careful regard is needed in framing flexible workplace policies and practices which take into account the differing operating constraints for large, medium and small businesses and for organisations operating in metropolitan, regional and remote areas. It is suggested that governments, employers' groups and community organisations develop models and ideas designed to support workplaces with varying conditions in support of carers.

##### **3. Public policy:**

- a. The Federal Government is strongly urged to play a greater leadership role by providing greater public recognition of, and financial and other assistance for, carers of the aged and people



- with disabilities. This should be based, *inter alia*, on a more comprehensive and finer understanding of local and regional caring requirements and capacities than is the case at present.
- b. Whole-of-government approaches are urgently needed which integrate responses in areas such as the provision of adequate housing, community and workforce awareness raising and greater availability of respite care for carers.
  - c. A Federal Carers Responsibility Act should be adopted, and new and innovative funding arrangements, such as a Carers Fund, should be carefully examined in consultation with carers themselves, employers and other interested stakeholders.

Many of the ideas about valuing carers and creating responsive workplaces are described in section 1.3.2 above. Additional verbatim comments in relation to public policy reforms included:

*Government should be forced to legislate for [people with] disabilities - they should be treated as a minority in the same way as we have special services for Aborigines - people with disabilities should have very special things set aside for them. (Focus group participant)*

*The Federal Government [should] take over disability and accommodation for the whole country. The Australian Constitution states that no person shall be disadvantaged by moving within and across States. And every single disabled person in this State, if they want to move to Melbourne they lose every service that they have and have to start from scratch. (Focus group participant)*

*Maybe the profit side [that is, for-profit businesses in the field of caring] should come out and it should all be run by government. It's a society issue and it's about how people live. (Focus group participant)*

*Centrelink should play a more active part. People should be able to go to them and ask about benefits and services. I found a social worker to look at my case. A hotline would be good for carers. (Focus group participant)*

*The Local Council would be a perfect location [for an information service]. It's close. You'd need one person, government funded, to tell you what support you can get. (Focus group participant)*

*The government wants to keep people in their own homes, so the government should fund this service. (Focus group participant)*

*If I thought I needed help, I should be able to back off and have a break. It needs to be a 24-hour service. (Focus group participant)*

*We need some sort of community care living fund – something that we all contribute to in the very early parts of our work life because we're all going to require some sort of care at some stage. (Roundtable expert)*



*We're calling on the Federal Government to look at a family carer's responsibility Act. It's important to remind the Government that the work's been done [Human Rights and Equal Opportunity Commission's report on balancing work and family] and there's been a lot of community and expert consultation. It's just such a shame that it's died. (Roundtable expert)*

*[There should be] greater investment in services of various descriptions that support families. The cash transfer of giving everyone a thousand bucks a year is okay but it isn't really working for us and we don't think it's really working for families. The community is very open to greater investment in services. (Roundtable expert).*

#### **4.4 Summary**

Consultations with members of the public and professionals working in the field of caring and working brought to light many compelling and, at times, deeply moving personal accounts, as well as suggestions for improving the situation for carers, particularly of the ageing and people with a disability.

In summary, the qualitative research revealed that:

1. Carers feel undervalued, and their experiences misunderstood by employers and co-workers.
2. Carers experience significant difficulties balancing work and caring responsibilities.
3. Carers feel that support services are inadequate and fractured across Government departments, as well as Federal and State/Territory Governments.
4. Carers experience a mismatch between their need for workplace flexibility and workplace practices.

In terms of the options for change, the qualitative research suggested that the most valuable reforms would ensure:

1. Greater recognition of the role of carers, both in the workplace and in the community generally (eg through awareness raising programmes).
2. Greater access to flexible work practices and greater consistency in implementation by managers within an organisation. This would be assisted by the introduction of a supportive legislative framework, such as HREOC's proposed Family Responsibilities and Carers' Rights Act. In addition, employers could introduce services which assist their employees to locate and access caring support services.
3. Enhanced access to, and quality of, aged and disability services, ie to reduce fragmentation and navigation (eg by introducing a one-stop-shop for carer information, advice and support). This outcome would be assisted by the conduct of a comprehensive review of national, State/Territory and local supports for carers, in which Federal/State/Territory Governments adopted a co-operative approach.



## 5. Key findings and recommendations

This report has clearly identified the need for reforms to enable employees to better balance their work and responsibilities to care for the aged and/or a person with a disability. TOCC is of the view that these reforms would benefit employers in terms of tapping into an under-utilised resource, and carers in terms of making real choices about the work/care dynamic.

In order to provide insights into the nature of the relationship between work and aged and/or disability care, this report has (i) reviewed the current policy landscape; (ii) provided new facts and figures; and (iii) revealed the voice of carers (both formal and informal). These data clearly identified the multi-faceted nature of the work/care dynamic, and the key roles played by Federal Government policy (including in relation to financial support, service provision and legislation) as well as workplace practices.

At the end of each chapter, conclusions were drawn about each of the topics for discussion, and the purpose of this chapter is to integrate those conclusions into key findings and make appropriate recommendations.

### 5.1 Key findings in relation to combining work and aged and/or disability care

With regard to the data as a whole, TOCC makes the following ten key findings:

1. **Being valued:** Carers currently feel undervalued, and that their experiences are misunderstood by employers and co-workers. This is reflected in the minimal level of service provision, as well as financial and workplace supports.
2. **Experience difficulties:** Carers experience difficulties balancing work and caring responsibilities: 34% of carers surveyed say that their job/career has suffered because of the competing demands of their caring responsibilities.
3. **Inadequate services:** Carers feel that support services are inadequate and fractured across Government departments, as well as Federal and State/Territory Governments.
4. **Costly services:** Government financial supports for carers are viewed as welfare, and not as a strategy to enable workforce participation. Accordingly financial supports are insufficient and 1 in 4 carers of the aged and/or people with a disability have reduced their hours of work because of the cost of care.
5. **Underuse of resources:** Carers represent an under-utilised workforce resource: nearly half (44%) of the carers surveyed chose a role below their skill level because it gives them the flexibility they need to balance work and caring responsibilities.
6. **Priority strategies:** The strategies which would most assist carers to balance their work and caring responsibilities are (i) improved access to



support services; (ii) greater workplace flexibility; and (iii) improved quality of support services.

7. **Workplace flexibility:** Carers find it difficult to access the full range of flexible work practices, and implementation varies across and within organisations.
8. **An issue for now and the future:** 1 in 4 Australians surveyed expect to care for an aged person and/or a person with a disability in the next 5 years, and workplace flexibility will be their key management strategy. 70% of respondents would like to manage these responsibilities by working more flexible hours, more than half (54%) by reducing their work hours, 50% by taking leave, and 41% by working from home.
9. **A strategic approach:** Resolving the dual work and care pressures more effectively requires a strategic and planned approach which integrates service provision, financial policies and workplace flexibility. This requires leadership, and co-operation, by Government, employer and carer stakeholders.
10. **A new legislative framework:** Current Federal anti-discrimination law does not provide sufficient protections for employees with caring responsibilities, nor impetus for the implementation of flexible work practices. Recent initiatives in the United Kingdom, including the introduction of legislation which provides employees with a "right to request" and employers with a duty not to "unreasonably refuse" such a request, provide Australia with a best practice model for change.

#### **Key recommendations in relation to combining work and aged and/or disability care:**

In terms of priority areas for reform to address these findings, TOCC makes the following five key recommendations:

1. **Service provision:** The Government/Opposition develop strategies to enhance access to, and the quality of, aged and disability services. These strategies should ensure the greater integration and resourcing of services.
2. **Workplace flexibility:** Employers ensure greater access to the full range of flexible work practices (ie beyond part-time work) for all carers (ie beyond the current focus on childcare). In addition, employers work towards greater consistency of implementation by managers across their organisations.
3. **Financial supports:** The Government/Opposition commit to increasing the level of financial supports for employees who are concurrently caring for an aged dependent and/or a person with a disability to enable real choices to be made about work and care.



4. **Legislation:** The Government/Opposition commit to introducing a Family Responsibilities and Carers' Rights Act, as recommended by the Human Rights and Equal Opportunity Commission.
5. **Review:** The Federal Government/Opposition commit to conducting a comprehensive review of public policy and employment strategies to assist employees to balance their work and caring responsibilities for the aged and people with a disability. This review should be conducted in concert with State, Territory and Federal Governments, aimed at creating a whole-of-government approach to enhancing service provision, and responsive to local and regional settings. It is recommended that the review committee comprise representatives from Governments (Federal, State/Territory), carer organisations, businesses and other interested parties. The aim of the review committee should be to launch a strategic plan, with specific actions, by 25 November 2008.





## Annexure

### 1. Australian benefits and allowances for carers

#### 1.1 Allowances

##### (a) Carer Payment

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

The Carer Payment is available to Australian residents providing constant care for:

- A person who has a physical, intellectual or psychiatric disability; or
- A child under 16 years of age with a profound disability or medical condition who has extremely high care needs; or
- Two or more children under 16 years of age with severe disabilities or medical conditions who together require an extremely high level of care; or
- An adult who has moderate care needs and that adult's dependent child if the child is less than 6 years of age (or up to 16 in limited circumstances).

In addition, the total hours that the carer works, studies or trains, including voluntary work and travel time, must not exceed 25 hours per week. The Carer Payment is also payable for up to 63 days in one calendar year during a period of respite or while the care receiver is in hospital.

The Carer Payment is both income and asset tested. The maximum fortnightly rate of Carer Payment is \$525.10 for singles, and \$438.50 for each member of a couple.

Under the income test, singles can earn up to \$132.00 per fortnight and remain eligible for the full Carer Payment. Singles who earn more than \$132.00 but less than \$1,459.25 per fortnight may be eligible for part-payment.

The assets test changed on 20 September 2007. Under the new rules, the value of the assets a claimant can have and still be eligible for the Carer Payment has increased significantly. A claimant will meet the new assets test if the value of their assets is below the following amounts (the value of the claimant's primary residence is not included in the assets test):

- \$520,750 for singles who are homeowners (up from \$343,750)
- \$641,750 for singles who are non-homeowners (up from \$464,750)



- \$825,500 combined, for couples who are homeowners (up from \$531,000)
- \$946,500 combined, for couples that are non-homeowners (up from \$652,000).

### **(b) Carer Allowance**

The Carer Allowance is a supplementary payment available to parents or carers who provide daily care and attention for adults or children with a severe disability or medical condition, who require additional care and attention. It is also available for carers of adults who are frail aged<sup>57</sup>. Both the carer and the person being cared for must be Australian residents. Carers of children must live in the same home as the child that they care for. Carers of adults (over 16 years of age) must provide the care in either their own home, or the home of the person they care for.

The Carer Allowance is not income or asset-tested and may be paid on top of wages, Carer Payment, or other payments, such as the Age Pension.

The Carer Allowance is a non-taxable fortnightly payment of \$98.50.

### **(c) Employment Entry Payment**

The Employment Entry Payment is a one-off payment, administered by Centrelink, which is intended to assist claimants with the costs associated with starting work.

An Employment Entry Payment is available to Australian residents:

- Who have been in receipt of the Carers Payment for more than 12 months; and
- Who start receiving earnings from work, or increased earning for their current work that disqualifies them from the Payment; and
- Whose new earnings are likely to last for four weeks.

The payment is \$104.00 for claimants who received the Carer Payment<sup>58</sup>.

## **1.2 Taxation benefits**

### **(a) Invalid relative tax offset**

A tax offset is available for Australian relatives who maintain a *dependent invalid relative*. An invalid relative is defined as a person who:

- is the carer's child, brother or sister;
- is 16 years or older; and
- receives a disability support pension; or
- has a certificate from an approved doctor certifying a continuing inability to work.

<sup>57</sup> Centrelink website: [www.centrelink.gov.au](http://www.centrelink.gov.au)

<sup>58</sup> Centrelink website: [www.centrelink.gov.au](http://www.centrelink.gov.au)



The invalid relative is considered 'maintained' if the carer lived in the same house as them, gave them food, clothing and lodging, or helped them to pay for living, medical and educational costs.

The maximum tax offset for the 2006-07 financial year was \$745 for each dependent invalid relative<sup>59</sup>. This amount is reduced in certain circumstances, for example, if the dependent's income was \$286 or more for the financial year, if the dependent was maintained for only part of the year, or if another person helped the carer maintain the dependent.

#### **Parent or spouse's parent tax offset**

A tax offset is available for Australian residents who maintain their parent, or their spouse's parent. The definition of 'spouse' covers both husband or wife, and de facto partners of the opposite sex.

A parent or spouse's parent is considered 'maintained' if the carer lived in the same house as them, gave them food, clothing and lodging, or helped them to pay for living, medical and educational costs.

The maximum tax offset for the 2006-07 financial year was \$1,489 for each dependent parent or spouse's parent<sup>60</sup>. This amount is reduced in certain circumstances, for example, if the dependent's income was \$286 or more for the financial year, if the dependent was maintained for only part of the year, or if another person helped the carer maintain the dependent.

### **1.3 Recent Government initiatives**

#### **One-off bonus payment (Federal Budget 2007-08)<sup>61</sup>**

The Federal Government allocated funding in the 2007-08 Budget to provide one-off tax-free payments to carers who receive the Carer Payment and/or the Carer Allowance.

In or about June 2007, recipients of the Carer Payment were provided with a one-off payment of \$1,000. This was also available to carers who are recipients of both the Carer's Allowance and either the Wife Pension or the Veteran's Affairs Partner Service Pension. Recipients of the Carer Allowance were provided with a one-off bonus of \$600.

The Carer Bonus is a discretionary budget allocation, and not an indexed annual payment.

#### **Disability Assistance Package**

The Australian Government has stated that it will provide funding of \$721.2 million over five years to provide families caring for a child with a disability with an annual payment of \$1000. The payment will be made for each child under 16 who qualifies their parent or carer for the Carer Allowance.

<sup>59</sup> Australian Taxation Office website: [www.ato.gov.au](http://www.ato.gov.au)

<sup>60</sup> Australian Taxation Office website: [www.ato.gov.au](http://www.ato.gov.au)

<sup>61</sup> 2007/2008 Australian Federal Budget at a Glance: [www.budget.gov.au](http://www.budget.gov.au)



The first payment was made in October 2007, and subsequent payments will be made annually in July<sup>62</sup>.

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<sup>62</sup> Department of Families, Community Services and Indigenous Affairs: <http://www.facs.gov.au>



## 2. Summary of Government supported Employed Carer Innovative Projects

<p><b>Name of organisation: NSW Orange Community Resource Organisation</b></p> <p><b>Project description</b></p> <p>The 'A Balance of Care' (ABC) Packages will enable working carers to receive a brokered package of up to \$2000 or \$4000 for higher care needs to provide a range of services to assist in reducing the time spent away from work and perhaps enable increased flexibility in undertaking additional hours or planned overtime.</p> <p>The "A Balance of Care (ABC) Packages will provide;</p> <ul style="list-style-type: none"><li>• Support in travel assistance to get the carers aged relative to and from doctors or specialist appointments,</li><li>• Meal and house keeping support,</li><li>• Temporary respite to enable the carer to attend a gym or social activities,</li><li>• Respite to improve income availability (eg overtime),</li><li>• Respite options such as facilitating day care placements or wellness drop-in services,</li><li>• Support for working carers undertaking overtime, and work related training,</li><li>• Support for carers to maintain their work hours or to reduce absenteeism in the work place.</li></ul> <p><b>Feedback: 02/09/2007, Wendy Coles, Commonwealth Carer Respite and Carelink Centre, Central West</b></p> <p><i>In September 2006 OCRO's Central West Commonwealth Carer Respite Centre received funding from the Commonwealth Government to operate a two year pilot project to develop support packages for working carers of frail older people in the Central West. The pilot programme known as A Balance of Care (ABC) Working Carer Packages, has been running for twelve months and over 60 carers have been assisted with support packages to help balance their working lives with their caring role.</i></p> <p><i>The pilot programme offers eligible carers a package valued at up to \$2000 which can be used to purchase services for the older person for whom they care including domestic assistance, transport to medical and other appointments, meal preparation, personal care, respite care and referral to ongoing services. In cases where the care recipient has high and complex needs, there is scope to offer a high needs package of up to \$4000.</i></p> <p><i>The ABC Packages are available to working carers, or carers seeking to work, who are the primary carers of frail older Australians.</i></p> <p><i>Carers participating in the programme come from across industry and business sectors, with many self-employed and farming families participating in the pilot. Employer participation has at this stage, been minimal, with an employer forum planned for 17 October 2007 in Orange, to inform business and industry and to determine the level of knowledge and flexibility in the workplace.</i></p>
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*The individually tailored packages offer the carer practical assistance to balance their working and caring roles, with the aim of also reducing absenteeism and the need to take paid or unpaid leave. Access to services for working carers may allow carers to remain in the workforce, to take advantage of training and other opportunities, and may reduce the loss of skilled workers and the need for expensive recruitment and training of new staff.*

*A number of carers have been exited from the packages for various reasons, ie: because the care recipient has passed away or been permanently placed into an aged care facility; or because a successful exit strategy has been negotiated between the carer and the provider of a suitable respite alternative such as a CACP, EACH or HACC services.*

**Name of organisation: Baulkham Hills Community Care**

**Project description**

To work closely with large Multi-national Companies in the Cumberland Prospect area, eg IBM, to provide education and support to both the working carer and the Human Resources Department and to tailor individual packages for carers. To establish links that will utilise the existing community care service providers by arranging an individual package of service for each carer/care recipient, including the promotion of residential respite options.

A case management component of ten weeks will be required to establish a rapport with the working carer/care recipient and establish their exact needs. This may include arranging visits with ACAT, networking and negotiating with other service providers in the Cumberland Prospect Region to input the care needs identified.

**Feedback: 25/08/2007, Judy Nicolson, Working Carers Liaison Officer, Hills Community Care**

*The Working Carers Liaison Project - the WCLP is one of eighteen Employed Carers Innovative Pilots funded by the Australian Government Department of Health and Ageing. Each of these pilots developed a model of assisting working carers, and received funding to trial their model for two years.*

*The Working Carers Liaison Project model focused on building partnerships with businesses and organisations, with the aim of reaching carers in those workplaces, who were needing assistance with their caring role. The Working Carers Liaison Project would then offer short-term case management (ten weeks) to assist these working carers to get services in place. Taking on the task of organising services on behalf of the working carer would reduce absenteeism, increase productivity, reduce carer stress and reduce the likelihood of resignation.*

*The Working Carers Liaison Project has experienced some difficulty in getting businesses and organisations to participate. At this point, halfway into the project, four key partnerships have been established. These are with Baulkham Hills Shire Council, Holroyd City Council, the Children's Hospital Westmead and Australia Post (Cumberland-Prospect area). The project has found that few*



referrals have been received via these partnerships. The majority of referrals have been via service providers, in particular Aged Care Assessment Teams and the Carer Respite Centre.

As at the end of August, the Working Carers Liaison Project has assisted 70 working carers. Some of these have only required information and referral, others have required case management. Feedback from working carers has been very positive. Having someone available to do the 'legwork', who knows how to navigate the system, and who can do the follow-up to ensure services commence has been seen as extremely worthwhile.

**Name of organisation: Feros Care Ltd**

**Project description**

The aim of the project is to test the viability of providing weekday respite care for rural and remote employed primary carers of elderly and frail recipients in the home of a community-based qualified personal carer. The Home Host Day Respite Project utilises a family-based daycare service model. Small and intimate groups (no more than 4 per carer) of elderly and frail recipients will be cared for in an approved home. Hours of operation for each home host will generally span 10 hours over 4 days but times can also be determined according to carer employment needs and personal preferences. The number of respite homes will increase from 2 to 6 (servicing between 24-50 carers) over the three-year funding period. What makes this project unique is that it targets rural and remote areas (including small coastal townships) where community infrastructure is not readily available for centre-based respite.

**Name of organisation: Tweed Valley Respite Services**

**Project description**

A flexible model of respite provision and other support services such as a 'Bridge to Work' component for working carers of frail aged persons and persons with dementia in the Tweed Shire with a particular emphasis on shift workers. This model will target both working carers and those intending to work. It will also provide a continuum of service for people as their care needs change.

**Name of organisation: VIC Villa Maria**

**Project description**

This project explores the idea of a Seniors Day Centre established within a large retail outlet in Oakleigh, South East Melbourne. The room or space would be appropriately located in the shopping/retail complex and be a place where the working carer could safely leave the frail aged person they care for, whilst they did their shopping.

**Name of organisation: Australian Home Care**

**Project description**

Provision of flexible and appropriate respite services for target carers while they undertake Certified Training Programmes as part of a Traineeship, or prior to employment with Australian Home Care or other suitable employer of their choice. Development of rigorous and validated tools for the mapping of life-skills competencies of informal carers in the community against Certified training competencies leading to opportunities for recognition of prior learning and



genuine new employment opportunities.
<b>Name of organisation: Northern Migrant Resource Centre</b>
<p><b>Project description</b></p> <p>Centre-based care located at a Community Respite House on weekdays and from existing premises on Saturdays.</p> <ul style="list-style-type: none"> <li>• The service will operate between 8:00 a.m. and 6:00 p.m.</li> <li>• Care recipients will be culturally and linguistically matched to the care environment. In the case of centre-based care, this means that each day session will be for one particular CALD group. Authentic ethnic meals will be provided, further adding to the sense of well-being. This matching is particularly important when providing personal care services, as there is often a cultural overlay with the way in which they are delivered.</li> <li>• <i>Spectrum</i> will provide the ability to tap into the employer network so as to identify potential employed carers and promote the programme. It will also be able to identify unemployed carers and be in a position to provide employer subsidies and training or re-skilling.</li> </ul> <p><b>Feedback: 02/09/2007 - Jo Krizmanic-Wilson, Aged &amp; Disability Services Manager</b></p> <p><i>I am from the Spectrum Migrant Resource Centre (formerly the Northern Migrant Resource Centre) in Victoria and we are providing adult daycare support to ageing people from migrant and refugee backgrounds in a community based setting that is ethno-specific. The groups operate across six days (Mon - Sat) for people from Italian, Macedonian, Vietnamese and Chinese backgrounds. All participants have a carer who is employed and the group has enabled carers to maintain their employment responsibilities whilst being comfortable with the fact that the person they care for (primarily their parent) is receiving support in a culturally appropriate manner. The groups each have bi-lingual staff and undertake culturally appropriate activities and ethno-specific meals are provided.</i></p>
<b>Name of Organisation: Carers Victoria, VIC</b>
<p><b>Project description</b></p> <p>Carers Victoria have developed Working Carers Options to provide tailored respite services to employed carers of frail aged, including those with dementia, in the North-West Region. This proposal seeks to identify the needs of carers at risk of leaving the workforce prematurely or unnecessarily by providing flexible and workable respite solutions. Working Carers Options seeks to provide pathways for carers who are seeking to re-enter the workforce and who are seeking more appropriate paid work than their caring responsibilities allow. Key Employer Partnership Respite Strategy initial discussions have commenced with Australia Post, Toyota Australia, RDNS, Melbourne Health and Baptist Community Care with the aim of developing a collaborative pilot programme to support employed carers.</p>




**Name of organisation: MS Limited**
**Project description**

A research project with 2 large employers with a total of 1,350 employees - the Leader Newspaper Group in Victoria and the Transport Accident Commission. The project will work with these public and private sector employers to specifically research and develop responses to establish carer need in their workforces.

**Feedback: 02/09/2007, Lisa Thomas, Working Futures Project Officer**

*I am the project officer for the Working Futures Project, auspiced by Multiple Sclerosis Limited. (Our project is a research project). Our project is drawing to a close. The literature review was completed at the end of 2006. We held an Employer Roundtable in May with Dr. Sharman Stone, Minister for Workplace Participation, with employers and employed carers in attendance. The roundtable was extremely successful.*

*The two participating workplaces (Transport Accident Commission - VIC and Leader Community Newspapers) have been surveyed, data has been analysed and the final report is going through the final stages of editing.*

*We were fortunate enough to receive some top-up funding from the FaCSIA and have therefore been able to report on carers caring for an individual under 65 in addition to the frail aged.*

*Whilst we had a low response with the survey, the data we received from participants is rich and provided us with a meaningful insight into the experiences of employed carers.*

**Name of organisation: QLD Blue Care**
**Project description**

A case management and "package care" approach that incorporates flexible respite options as well as linking carers seeking to work with appropriate employment agencies and options. A comprehensive assessment will be conducted to develop a respite care plan that incorporates the needs of the care recipient and carer and draws on both formal and informal supports. Part of the care plan will include formal handover to existing services. The carers needs for education/training and employment related issues will also be factored into the respite plan, drawing in the employer where appropriate.

**Name of organisation: SA Resthaven**
**Project description**

"Employed Carers: Expanding the Options" will collaborate with employers to research the needs of employed carers (of frail older people) in three workforces: two industrial (Arnott's Biscuits Limited, Hills Industries), and one health based (Lyell McEwin Health Service). Innovative and flexible responses to support employed carers to remain in the workforce, or to return to the workforce, will be trialled during the project period. Review of community care policy and procedures, and the interaction/correlation with employment policy, in responding to the needs of employed carers, will be a key component of the project. Systems to integrate processes into workplaces to sustain the outcomes of the project for



employed carers will be recommended to employers. The outcomes for employed carers and employers will be evaluated through the duration of the project, with an interest in the impact different workforces, work sites and respite models have on the project outcomes.

**Feedback: 02/09/2007, Quynh Vu, Project Manager**

*The employed Carers: Expanding the Options is funded by the National Respite for Carers Programme. Resthaven has been offered funding to run this pilot project for 2 years, and will be working in collaboration with 3 key employers; Lyell McEwin Health Services, Hills Industries and Arnott's Biscuit Limited.*

*The objective is to act as an incentive for increase workforce participation of employed carers by offering community services that are responsive to the needs of employed carers*

*Where carers have been identified immediate services can be implemented. To enable clients to have access to a holistic package of services additional options sourced may include services through councils, existing respite services and other community services.*

*The Project is progressing successfully following an initial slow uptake of services. The majority of access to the programme is from the hospital based staff, whom we believe to have a greater insight into the understanding of the term carer and offer of support, if only because it is their core business supporting others. Generally further referrals then result by word of mouth and speaking with other staff that are recommending the programme, trusting the service, and recognising the personal benefits.*

*Extensive marketing has been initiated within each industry, by accessing and speaking at meetings to all levels of staff, including availability to 'capture shift changeovers' at any time in a 24 hour clock to suit specific sites.*

*'Unpacking' the notion of the informal carer role, and the myth that we believe we can manage it all ourselves, has been the most challenging process. Flyers and posters were distributed, including interpretation in several languages. It is beneficial that we spend significant lengths of time at sites for easy and instant access and availability. Wide regional areas covered include the Barossa Valley, Southern and Western regions and Adelaide Hills.*

**Name of organisation: ACH Group**

**Project description**

The 'Worksouth' project brings together industry, local government and aged care. ACH will work with two large employers (Mitsubishi and Solar Optical) to better understand the needs of their employees who are primary carers of the frail aged and to develop new and innovative approaches to the provision of respite support. Will draw on existing ACH infrastructure to provide extended centre-based day programmes with operating hours that align with work shifts.

**Name of organisation: Helping Hand**

**Project description**



The Project will provide respite support to 21 shift workers over a period of three days each week. It covers two of the three shifts that usually occur over a 24-hour period. A mixed service model combining one-on-one in-home and host-home respite will be implemented, including the development of 6 host-homes across the northern and western metropolitan areas of Adelaide. The project will work with local employers and job network agencies to achieve the project objectives.

**Feedback: 26/09/2007, Claire Kernich, Co-ordinator Shift Worker Respite Project, Helping Hand Aged Care Inc.**

*Our Employed Carers Innovative Project has been slow to get off the ground but we are getting there. It is called the Shift Worker Respite Project. Our model looks at providing respite to working or studying carers who live in north and west metro Adelaide who care for someone who is frail elderly (including those with dementia/challenging behaviours). Respite is provided as a combination of attending a small group in a worker's host-home and also one-to-one respite in the client's own home which can be provided directly before or after attending the host-home, one day a week.*

*We have two host-homes established in metro Adelaide, providing 3 days of respite. Mondays in Salisbury and Tuesdays and Fridays in Greenwith. We also have the capacity to utilise our respite cottage, Joy's Retreat in Woodville, in the west, as we have not been able to secure a host-home worker in the region. We currently have vacancies at all host-home venues and are actively seeking referrals. We are also still looking to recruit care workers with Certificate 3 who live in north or west metro Adelaide who would like to run a host-home at their house one day a week.*

**Name of organisation: WA Southern Cross Care**

**Project description**

Southern Cross Care propose to provide employed carers with a designated support worker to shoulder some of the responsibility of managing those care needs which take carers away from their work responsibilities eg: medical appointments, pharmaceutical management, hairdresser, dentist, optometrist appointments, visiting during hospital stays etc. Offering up to 50 carers a total of 1-5 hours per month.

**Name of organisation: Mandurah**

**Project description**

Mandurah Retirement Village have approached large local employers across a range of sectors, (Health Campus, Alcoa, Coolibah Lodge, Chamber of Commerce and Industry and the City of Mandurah) to offer up to 6 working carer respite places for each employer. Clients will be able to access pre and post work in-home supports of up to 3-4 hours per week and these in home respite time periods will link directly with day based respite at either MRV Day Respite Centre or Daycare Services currently being accessed at Peels Adult Day Care Centre. MRV's ECIPS will be offered across a 10-hour period of the day from 8 am to 6pm. Some flexibility in the provision of in-home respite is welcome. However the Respite House will be open between these specified periods.



Services will include: in-home respite pre/post work operating Monday to Sunday, 365 days a year. Centre based weekend services will only be provided at MRV ECIPS Respite House, as the Regions current adult day services do not operate on the weekends. This initiative aims to support working carers that also work across the week, not just weekdays. Mandurah is a major metropolis for aged persons and industries targeted through this initiative operate some services 7 days a week. Therefore flexible provision of working carer respite on weekends is essential to support carers who wish to maintain their work-life responsibilities whilst maintaining their family caring capacity.

**Feedback: 24/09/2007, Stella Millican, Coolibah Total Caring**

*The greatest challenge is still getting working carers to access the service. What we are finding is that some are using the service as a stopgap prior to permanent placement.*

*But the carers that have been on the programme for over 6 months now are very happy with services.*

*Last Saturday we organised a fun day at Fairbridge. Carers and Care recipients and some other NRCP clients and staff were invited to Fairbridge for a day of pampering. We invited the Alzheimers Association to provide training for Carers, which they did at no cost. It was a great day. Will evaluate day when surveys are handed in.*

**Name of organisation: Carers ACT**

**Project Description**

Carers ACT propose a range of innovative home visitation and monitoring services. They wish to examine volunteer and in-home sitting services such as those in operation in the UK, to determine suitability for the ACT. They propose that in-home supports be made available to Carers whose care recipients would not suit a Cottage or Centre Based Respite Model. This group of carers identified in-home supports including: home visits during work hours to assist the care recipient in organising doctors appointments or a periodic visit to the home to ensure the care recipient was safe and well. Carers ACT have identified the key priority respite needs of this target group in order that they may continue or re-enter the full-or part-time workplace.

**Name or organisation: Home Flexicare Baptist Community Care**

**Project description**

The Baptist Community Services NSW & ACT will utilise established aged care facilities to provide respite in a daycare centre. Providing flexible day respite and overnight respite in emergency situations for up to 10 carers per week at 2 locations (Morling Lodge and Carey Gardens) 7am - 7pm. Meals and transport provided.

**Feedback: 26/09/2007, Iris Malone, Daybreak Coordinator, BCS Community Centre**

*The programme has been up and running since 15 January. To date we have assisted 14 carers and there are currently 6 clients attending the centre. Three full-time and three part-time. The centre is open 8am to 6pm Monday to Friday.*



*Activities include outings (eg Floriade, lunch at the club), daily exercises, and a variety of games that include physical, cognitive, creative and cultural aspects.*

*Interaction and participation with those able residents of our low care facility has been a great success. These activities include bus trips, games and a great favourite of both groups are the movie sessions with the popcorn and lollies included.*

*Our courtyard gardens are looking great with all the attention they get from the clients and this is a great place for them to have their BBQ lunches and home baked morning teas.*

*Carers remark that they would be unable to remain in the workforce if it were not for Daybreak.*

*We provide assistance with such things as hairdressing (mobile), appointments ie doctor, physio etc. We will either meet the carer or take the client to the appointment (if appropriate). All this makes it easier for the carer and enables them spend more time at work.*

**Name of organisation: Carers NT Inc**

**Project description**

The proposed model is based upon the Family Day Care model that has provided services to parents of children since 1977.

People currently providing care for their ageing relatives, or who have provided care, will be recruited to provide in home care for up to 20 ageing Australians in each of Darwin urban, Darwin rural and Katherine areas. The programme will provide carers with self-employment opportunities. They will be selected based on personal attributes as well as appropriateness of residence. Carers will be provided with support, training, and supervision from a paid employee of Carers NT with experience in aged care, which will offer telephone and face-to-face assistance.

The project is proposing to pay a rebate to the employed carer in line with the childcare rebate. Currently this rebate is a maximum of \$6.00 per hour and reduces according to family income. The rebate will be paid from the project funds.



### 3. Australian anti-discrimination legislation regarding work and caring responsibilities

#### **Sex Discrimination Act 1984 (Cth)**

The *Sex Discrimination Act 1984* (Cth) prohibits direct discrimination in relation to dismissing an employee on the ground of family responsibilities, and direct and indirect discrimination on the basis of sex in relation to employment.

'Family responsibilities means responsibilities of the employee to care for or support: (a) a dependent child of the employee; or (b) any other who is in need of care and support' (section 4A).

#### **Disability Discrimination Act 1992 (Cth)**

Employed carers receive some protection from discrimination in employment under this legislation. The *Disability Discrimination Act 1992* (Cth) (Act) provides some protection against discrimination for workers who are 'associates' of a person with a disability. 'Associate' is defined in the Act to include a carer.<sup>63</sup>

Section 15 of the Act provides that it is unlawful for an employer to discriminate against a person on the ground of a disability of any of that person's associates:

- In the arrangements made for determining who should be offered employment;
- In determining who should be offered employment;
- In the terms or conditions of employment;
- By denying the employee access, or limited the employee's access, to opportunities for promotion, transfer or training, or to any other benefits associated with employment;
- By dismissing the employee; or
- By subjecting the employee to any other detriment<sup>64</sup>.

#### **Anti-Discrimination Act 1977 (NSW)**

Under the *Anti Discrimination Act 1977* (NSW) (Act), a carer is defined as a person who has responsibilities to care for or support:

- Their child (including step-child, foster child, child of their de facto);
- Any adult of whom they are the legal guardian; and
- Any immediate family member (including spouse, grandchild, parent, grandparent, brother or sister, spouse's parent, spouse's grandchild, spouse's grandparent, spouse's brother or sister).

It is unlawful, under s49V of the Act for an employer to discriminate against a person on the ground of the person's responsibilities as a carer:

- In the arrangements the employer makes for determining who should be offered employment;
- In determining who should be offered employment;

<sup>63</sup> *Disability Discrimination Act 1992* (Cth) section 4.

<sup>64</sup> *Disability Discrimination Act 1992* (Cth) section 15(1) and (2).



- In the terms or conditions of employment;
- By denying the employee access, or limiting the employee's access, to opportunities for promotion, transfer or training, or to any other benefits associated with employment;
- By dismissing the employee; or
- By subjecting the employee to any other detriment<sup>65</sup>.

However, the legislation provides employers with a defence to a claim of unlawful discrimination – with respect to recruitment and termination of employment – in circumstances where:

- The carer would be unable to carry out the inherent requirements of the particular employment; or
- The carer would, in order to carry out those requirements, require arrangements that are not required by persons without those responsibilities as a carer, and the making of such arrangements would impose unjustifiable hardship on the employer.

### **Equal Opportunity Act 1995 (Vic)**

In Victoria, the *Equal Opportunity Act 1995* (VIC) prohibits discrimination against job applicants and against employees on the grounds of parental status, or status as a carer<sup>66</sup>. 'Carer' is defined in section 4 as a 'person on whom another person is wholly or substantially dependent for ongoing care and attention, other than a person who provides that care and attention wholly or substantially on a commercial basis.'

Section 23 however, provides an exception for employers based upon the 'reasonable and genuine' requirements of employment.

### **Discrimination Act 1991 (ACT)**

In the Australian Capital Territory, it is unlawful for an employer to discriminate against a person on the grounds of their status as a parent or carer<sup>67</sup>, in the arrangements made for deciding who should be offered employment, and in the terms and conditions on which employment is offered<sup>68</sup>.

Further, it is unlawful for an employer to discriminate against an employee, on the grounds of their status as parent or carer<sup>69</sup>, in the terms or conditions afforded to the employee, by denying or limiting the employee's access to promotion, training and other benefits, by dismissing the employee or by subjecting the employee to any other detriment<sup>70</sup>.

'Carer' is defined in the Dictionary of the Act: 'A person is a carer of someone else (the dependent) if the dependent is dependent on the person for ongoing care and assistance, and the person cares for the dependent otherwise than because of a commercial arrangement or because of a substantially commercial arrangement.'

<sup>65</sup> *Anti-Discrimination Act 1977* (NSW) section 49V.

<sup>66</sup> *Equal Opportunity Act 1995* (Vic) sections 6, 13 and 14.

<sup>67</sup> *Discrimination Act 1991* (ACT) section 7.

<sup>68</sup> *Discrimination Act 1991* (ACT) section 10(1).

<sup>69</sup> *Discrimination Act 1991* (ACT) section 7.

<sup>70</sup> *Discrimination Act 1991* (ACT) section 10(1).



### **Anti-Discrimination Act 1991 (Qld)**

In Queensland, the legislation provides that a person must not discriminate on the grounds of parental status or family responsibilities<sup>71</sup> in either the pre-work area (for example in deciding who should be offered work)<sup>72</sup>, or in the work area (for example by denying opportunities for promotion or transfer, by dismissing the worker or by treating the worker unfavourably)<sup>73</sup>.

However, section 25 provides that an employer may impose genuine occupational requirements for a position.

'Family responsibilities' of a person are defined in the Dictionary of the Act as the person's responsibilities to care for or support a dependent child of the person, or any other member of the person's immediate family who is in need of care or support.

### **Equal Opportunity Act 1984 (WA)**

In Western Australia, it is an offence to discriminate against a person on the grounds of that person's family responsibility or family status:

- In the arrangements made for determining who should be offered employment;
- In determining who should be offered employment;
- In the terms or conditions on which employment is offered;
- In the terms and conditions of employment afforded to an employee;
- By denying or limiting the employee access to promotions and training;
- By dismissing the employee; or
- By subjecting the employee to any other detriment<sup>74</sup>.

Under the Act, a person (the discriminator) discriminates against another person (the aggrieved person) on the grounds of family responsibility or family status, if, on the grounds of the actual or imputed family responsibility or family status of the aggrieved person, the discriminator treats the aggrieved person less favourably than the discriminator would treat another person in the same circumstances.

Furthermore, the discriminator is defined to discriminate against the aggrieved person if they require compliance with a requirement or condition:

- With which a substantially higher proportion of persons without the family responsibility or family status of the aggrieved person comply or are able to comply;
- Which is not reasonable having regards to the circumstances of the case; and
- With which the aggrieved person does not or is not able to comply<sup>75</sup>.

Under the Act, 'family responsibility or family status', in relation to a person is defined as:

<sup>71</sup> *Anti-Discrimination Act 1991 (Qld)* section 7.

<sup>72</sup> *Anti-Discrimination Act 1991 (Qld)* section 14.

<sup>73</sup> *Anti-Discrimination Act 1991 (Qld)* section 15.

<sup>74</sup> *Equal Opportunity Act 1984 (WA)* section 35B(1) and (2).

<sup>75</sup> *Equal Opportunity Act 1984 (WA)* section 35A(1) and (2).





- Having responsibility for the care of another person, whether or not that person is a dependant, other than in the course of paid employment;
- The status of being a particular relative; or
- The status of being a relative of a particular person.

### **Anti-Discrimination Act 1992 (NT)**

In the Northern Territory, discrimination is prohibited on the grounds of parenthood (rather than on the grounds of being a carer)<sup>76</sup>. This would nevertheless apply to parental carers of disabled children.

It is an offence under the *Anti-Discrimination Act 1992* (NT) to discriminate on the grounds of parenthood:

- In deciding who should be offered work;
- In the terms and conditions of the work offered;
- In failing or refusing to offer work or access to a programme such as vocational training;
- In the variation of the terms and conditions of work;
- In failing or refusing to grant opportunities such as promotion and transfer;
- In dismissing a worker; or
- By treating the worker less favourably in any way in connection with work<sup>77</sup>.

### **Anti-Discrimination Act 1998 (Tas)**

In Tasmania, it is unlawful to discriminate against a person engaged in, or undertaking, any activity in connection with employment<sup>78</sup> on the grounds of their family responsibilities<sup>79</sup>. However, an employer may discriminate against a person on the ground of family responsibilities if that person requires special services and facilities, and the supply of which would impose unjustifiable hardship on the employer<sup>80</sup>.

'Family responsibilities' is defined in the Act as the responsibility to care for or support a child who is wholly or substantially dependent or any other immediate family member who is in need of care or support. 'Immediate family member' in relation to a person is defined as a spouse or partner of that person, an adult offspring, child, parent, grandparent, grandchild or sibling of the person or of a spouse or partner of the person<sup>81</sup>. Therefore, carers of adult family members are protected under this Act.

### **Equal Opportunity Act 1984 (SA)**

Carers are not expressly protected from discrimination in the workplace or in connection with employment under South Australian legislation. The *Equal Opportunity Act 1984* (SA) limits its prohibition of discrimination to the grounds of (relevantly) sex, sexuality, marital status and pregnancy.

<sup>76</sup> *Anti-Discrimination Act 1992* (NT) section 19.

<sup>77</sup> *Anti-Discrimination Act 1992* (NT) section 31(1) and (2).

<sup>78</sup> *Anti-Discrimination Act 1998* (Tas) section 22(1)(a).

<sup>79</sup> *Anti-Discrimination Act 1998* (Tas) section 16.

<sup>80</sup> *Anti-Discrimination Act 1998* (Tas) section 28.

<sup>81</sup> *Anti-Discrimination Act 1998* (Tas) section 3.



## 4. Summary of international initiatives and legislation regarding work and care

### 4.1 UNITED KINGDOM

#### 4.1.2 Legislation

##### **Work and Families Act 2006 (UK)**

###### *Background*

In 2002, the *Employment Act* introduced new rights for working parents by amending the *Employment Rights Act 1996* (UK) with the insertion of a new section 80F. Section 80F *Employment Rights Act 1996* provides parents with the right to request flexible working arrangements subject to certain statutory conditions. The regulations provide that the employee must have been continuously employed for no less than 26 weeks and must be the mother, father, adopter, guardian or foster parent (or the partner of, or married to, one of those people) of the child concerned.<sup>82</sup>

*New amendments (effective as of April 2007) applicable to carers: entitlement to request contract variation*

Section 12 of the *Work and Families Act 2006* amends section 80F of the *Employment Rights Act 1996* to widen the scope of the existing right to request flexible working arrangements. In particular, persons who have caring responsibilities for adults are now permitted by statute to apply to their employer for flexible working conditions.

Section 80F *Employment Rights Act 1996* (in conjunction with the *Flexible Working (Eligibility, Complaints and Remedies) (Amendment) Regulations 2006*) now provides that a qualifying employee may apply to their employer for a change in the terms and conditions of their employment, if the change relates to:

- the hours they are required to work;
- the times they are required to work; or
- the place (ie home or place of business) they are required to work.

The purpose of applying for the change must be to enable the employee to care for someone who is:

- a child under 6 years of age; or
- a disabled child (as defined in the regulations) under 18 years of age<sup>83</sup>;  
or
- a person aged 18 years or over who requires care.

In order to be eligible to apply for flexible working conditions (in respect of an application for the care of an adult) the employee must have been continually employed for not less than 26 weeks and must be, or expect to be, caring for a person in need of care who is either married to, the partner, or the civil partner,

<sup>82</sup> UK Parliament, Explanatory Notes to Work and Families Act 2006 (Chapter 18).

<sup>83</sup> *Flexible Working (Eligibility, Complaints and Remedies) (Amendment) Regulations 2006*, regulation 5.



of the employee, a relative of the employee, or living at the same address as the employee.

The regulations define 'partner' to include a member of a heterosexual or homosexual couple who are living together as husband and wife, or as civil partners. The regulations provide a wide definition of 'relative', to include adoptive relationships, step-relationships, parents-in-law, guardians and 'special guardians'.<sup>84</sup>

The regulations do not require a specific level of care to be provided by the carer before he or she has the right to request flexible working conditions.

#### *Employer's right to refuse an application for flexible working*

Section 80G(1)(b) of the *Employment Act 2002* (UK) provides that an employer shall only refuse an application (as described above) if they consider that one or more of a specified list of grounds applies. The grounds for refusal include the burden of additional costs, detrimental effect on ability to meet customer demand, detrimental effect on quality or performance and the inability to re-organise work among existing staff.

#### ***Carers (Recognition & Services) Act 1995 [as amended by Carers and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004]***

Under these three pieces of legislation, carers who provide, or intend to provide, a substantial amount of care on a regular basis are entitled to a 'carer's assessment'.

A carer's assessment is carried out by a representative of the UK social services authority and must address two distinct issues:

- the sustainability of the caring relationship; and
- the work, education and leisure needs of the carer.

In addressing these issues, the assessor must consider the carer's ability to provide and continue to provide care, taking specific consideration of whether the carer works or wishes to work, or undertakes or wishes to undertake education, training or any leisure activity.<sup>85</sup>

The purpose of the carer's assessment is to develop a care plan for the carer and person being cared for. The assessor will determine, and include in the plan, the services that should be provided to the disabled person and/or the carer. Such services may include, for example, the provision of help with housework and taxis to work to minimise the carer's time.<sup>86</sup>

In the Practice Guidance to the 2000 Act, assessors are advised of the following:

*carers should be supported to stay in work or return to work, where this is what they want to do. The local council should therefore.....audit services to identify how well they support carers through providing*

<sup>84</sup> *Flexible Working (Eligibility, Complaints and Remedies) (Amendment) Regulations 2006*, regulation 3.

<sup>85</sup> *Carers (Equal Opportunities) Act 2004*, section 2.

<sup>86</sup> Carers UK (2007) *Carers and their Rights* London, UK.



*flexible and reliable packages of care which allow carers to continue to work<sup>87</sup>*

Eligibility for an assessment, as discussed, is that the carer provides a substantial amount of care on a regular basis. 'Substantial' and 'regular' are not defined in the legislation. However, the Practice Guidance to the 2000 Act provides the following assistance:

*In any given situation, the test that a practitioner should apply will relate to the impact of the caring role on the individual carer. In particular the practitioner will need to address the following questions: is the caring role substantial? How great is the risk of the caring role becoming unsustainable?<sup>88</sup>*

#### **4.1.2 Allowances**

##### **Carer's Allowance**

The Carer's Allowance is the main state benefit for carers in the UK. The allowance is means-tested and subject to the satisfaction of certain conditions. To be eligible to receive the carer's allowance, the carer must be over 16 years of age, living in the UK and caring for someone for at least 35 hours per week. The carer must not be a full-time student and must not earn more than £87 per week (although this excludes income tax, national insurance and half the carer's pension contributions). The carer must not receive any of the list of other benefits (including maternity allowance, state retirement pension and incapacity benefit). Finally, the person being cared for must receive a qualifying disability benefit.<sup>89</sup>

The Carer's Allowance is currently (for the 2007/2008 financial year) a payment of £48.65 per week.

##### **Income Support and Carer's Premium**

Carers may also be entitled to Income Support if they are not in paid work, or are working for less than 16 hours a week. Income support is means tested and to be eligible, the carer must not have savings over £16,000. Carers with savings between £6,000 and £16,000 will be entitled to a reduced benefit.

The amount of Income Support available depends upon the applicant's age, the income of non-dependents living with the applicant, the applicant's caring responsibilities and any disability of a dependent living with the applicant. The maximum amount for single applicants over 25 is currently £59.15 per week. The maximum benefit for couples over 25 is currently £92.80 per week.

Income Support is available in addition to the Carer's Allowance. Carers who are eligible for both Income Support and the Carer's Allowance are also entitled to a Carer Premium of £27.15 per week.

##### **Disabled Child Premiums**

<sup>87</sup> *Carers and Disabled Children Act 2000* (UK): Carers and people with parental responsibility for disabled children: Practice Guidance (see [www.carers.gov.uk/carersdisabledchildact2000.htm](http://www.carers.gov.uk/carersdisabledchildact2000.htm)).

<sup>88</sup> *Carers and Disabled Children Act 2000*: Carers and people with parental responsibility for disabled children: Practice Guidance, paras 67-8.

<sup>89</sup> <http://www.direct.gov.uk>.



Carers responsible for children under 19 years of age will be entitled to the Disabled Child Premium if the child is eligible for, and receiving, the Disability Living Allowance, or if the child is blind. A carer may also be entitled to the Enhanced Disability Premium (child) if the child receives the highest rate of Disability Living Allowance and does not have capital of more than £3,000.

#### **4.1.3 Taxation benefits**

##### **Child Tax Credit**

Carers of children may be entitled to the Child Tax Credit, with an additional credit for children with disabilities. To be eligible, the applicant must be over 16 years of age, living in the UK and be the primary caregiver for the child. The credit is means tested with a family income cap of £58,175 per annum or £66,350 for families with children under 12 months of age.

##### **Working Tax Credit**

The Working Tax Credit is available to carers of children who are over 16 years of age and work at least 16 hours a week. The carer will receive an additional benefit if the child they care for has a disability.

## **4.2 NEW ZEALAND**

### **4.2.1 Legislation**

#### **Human Rights Act 1993 (NZ)**

Under this Act, carers have some legal rights not to be discriminated against in employment. The prohibited grounds of discrimination under the Act include discrimination on the ground of family status, which is defined to include 'having responsibility for part-time or full-time care of children or other dependents.'<sup>90</sup>

Another prohibited ground of discrimination is disability. While most carers do not have disabilities themselves, the prohibited grounds of discrimination under the Act apply also to relatives or associates of the person with a disability.<sup>91</sup>

Under section 22 of the Act, it is unlawful for an employer, by reason of the prohibited ground of discrimination, to:

- refuse or omit to employ the applicant where work is available;
- offer or afford the applicant or employee less favourable terms of employment, conditions of work, benefits, and opportunities (such as training and promotion) as that offered or afforded to applicants with the same capabilities;
- terminate or retire the employment of the employee;
- subject the employee to any detriment.<sup>92</sup>

It is also unlawful for a person concerned with procuring employment to treat a person differently from other persons in the same circumstances by reason of any of the prohibited grounds of discrimination.<sup>93</sup>

<sup>90</sup> Human Rights Act 1993 (NZ) section 21(l).

<sup>91</sup> Human Rights Act 1993 (NZ) section 21(2).

<sup>92</sup> Human Rights Act 1993 (NZ) section 22(a)-(d).



### **Parental Leave and Employment Protection Act 1987 (NZ)**

This Act gives employees the right to a maximum of 14 weeks parental leave, and a maximum of 52 weeks extended leave in some circumstances. However, the Act does not provide any additional support to parents caring for children with special needs (such as disabilities).<sup>94</sup>

#### **4.2.2 Allowances**

Unlike the position in Australia and the UK, there is no single carers' benefit that accounts for all carers in different circumstances.<sup>95</sup> The New Zealand Social Security programme (under the *Social Security Act 1964* (NZ)) provides, however, for carers' benefits in specific circumstances as outlined below. It is worth noting that in New Zealand, the benefits available to carers are secondary to those provided to the person requiring care.<sup>96</sup>

#### **Domestic Purposes Benefit**

The Domestic Purposes Benefit is available to caregivers of the sick or infirm in certain circumstances. A caregiver will be entitled to this benefit if he or she is:

- over 16 years of age; and
- caring full-time for someone (but not his or her partner) who would otherwise require hospital care, rest home care, residential care provided for severely disabled children and young people, or care of a similar kind.

The benefit, as at 1 April 2007, is an income tested weekly payment of NZD\$223.10 (for singles over 18 years of age), NZD\$293.08 (for sole parents) or NZD\$185.92 (for carers living with a partner).

The caregiver is eligible for the whole entitlement if he or she earns less than NZD\$80 a week, or NZD\$4,160 a year (before tax). If the carer earns between NZD\$4,161 and NZD\$9,360 per year, the benefit is reduced by 30 cents for each dollar of their income. If the carer earns over NZD\$9,361 annually, the benefit is reduced by 70c for each dollar of their income.

However, if the carer pays for childcare while he or she works, he or she may be eligible to earn NZD\$20 a week over the above thresholds.

#### **Child Disability Allowance**

The Child Disability Allowance is available for the parent or guardian of a child with a serious disability child who lives at home and requires constant care and attention. The allowance is a fortnightly, non-means-tested, non-taxable payment of NZD\$78.94.

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<sup>93</sup> *Human Rights Act 1993* (NZ) section 22(2).

<sup>94</sup> 'Family Carers: A review of New Zealand Legislation and Related Strategies', September 2006, New Zealand Carers Alliance, Carers New Zealand and Palairet Law.

<sup>95</sup> New Zealand Carers Alliance, Carers New Zealand and Palairet Law, *Family Carers: A review of New Zealand Legislation and Related Strategies*, September 2006, p. 26.

<sup>96</sup> New Zealand Carers Alliance, Carers New Zealand and Palairet Law, *Family Carers: A review of New Zealand Legislation and Related Strategies*, September 2006, p. 27.



To qualify for this allowance, the carer must:

- be the main caregiver of a child; or
- have care and control of the child for the time being if there is no main caregiver.

In addition, the child must:

- have a serious physical or intellectual disability; and
- be under 18; and
- need constant care and attention for at least 12 months because of their disability.

The allowance may also be available when the disabled child lives in a home or hostel and the child's parent or guardian is required to contribute to the costs of maintaining them.

### **Disability allowance**

This allowance (which can be received in conjunction with income support such as an Invalid Benefit) is an indirect benefit to carers. The allowance provides non-taxable income-tested assistance to people who have ongoing costs because of their disability. The maximum payment, as at 1 April 2007, is NZD\$52.38 per week. The payment would alleviate, for the carer, some of the costs incurred in caring for a person with a disability.

### **Other**

Apart from the Domestic Purposes Benefit and Child Disability Allowance, there is no specific carer allowance or payment, so a carer's ability to access income support is dependent on accessing other benefits, such as those available to low income earners.<sup>97</sup>

#### **4.2.3 Taxation benefits**

There are several taxation benefits available for carers of children, such as the child tax credit, family tax credit (previously called family support), in-work tax credit and parental tax credit.

#### **4.2.4 Government policy**

In August 2006, the New Zealand Federal Government published a 10-year plan entitled 'Choices for Living, Caring and Working'. One element of the plan is a commitment to work towards improving the choices of New Zealanders who are caring for adults of all ages, including older people and those with ill health and/or disability.

The report proposes to address the current issues faced by carers in the following ways:

- the exploration of work-life balance solutions for people with multiple care responsibilities, the provision of additional unpaid leave to carers, and the right to request flexible working arrangements; and

<sup>97</sup> New Zealand Carers Alliance, Carers New Zealand and Palaret Law, *Family Carers: A review of New Zealand Legislation and Related Strategies*, September 2006, Appendix 1, p. 58.



- working to improve services and support for beneficiaries, including those with caring responsibilities.<sup>98</sup>

## 4.3 CANADA

### 4.3.1 Legislation

#### **Employment Insurance Act 1996 – Compassionate Care Benefit**

Section 23.1 of the Federal *Employment Insurance Act 1996* (CAN) introduced 'compassionate care benefits' in 2004 for people wishing to provide care to a gravely ill family member who is at risk of dying within 26 weeks.

The benefit entitles the carer to be paid for up to a maximum of six weeks during which they have been absent from work due to their caring responsibilities. The basic benefit rate is 55% of the carer's average insured earnings, up to a yearly maximum insurable amount of \$40,000.00. Carers who also receive the Child Tax Benefit may be entitled to a higher benefit rate.

To receive the benefit, the carer must provide medical proof (a certificate signed by the family member's doctor) showing that the ill family member needs care or support and is at risk of dying within 26 weeks.

In addition, the carer must be able to show that:

- their regular weekly earnings from work have decreased by more than 40%; and
- they have satisfied the qualifying period (that is, the accumulation of 600 insured hours in the last 52 weeks).

The carer may still work whilst receiving the benefit and may earn up to CAN\$50 per week (or CAN\$75 per week in 23 participating economic regions) without having their benefit reduced. Any monies earned above the \$50 (or \$75) will be deducted dollar for dollar from the carer's benefit.<sup>99</sup>

#### **Anti-discrimination legislation**

Canada has two principle pieces of legislation dealing with discrimination in the workplace, namely the *Employment Equity Act 1995* (CAN), and the *Canadian Human Rights Act 1985* (CAN). However, neither Act provides specific protection for carers.

### 4.3.2 Taxation Benefits

#### **Canada Child Tax Benefit (CCTB)<sup>100</sup>**

The CCTB is a non-taxable amount paid monthly to help eligible families with the costs of raising children under 18 years of age. The CCTB may include the National Child Benefit Supplement (NCBS) and the Child Disability Benefit (CDB).

To be eligible for the CCTB, the applicant must live with a child under 18 years of age and be primarily responsible for the care and upbringing of the child.

<sup>98</sup> New Zealand Federal Government, *Choices for Living, Caring and Working*, August 2006.

<sup>99</sup> Service Canada, *Employment Insurance Compassionate Care Benefits* (at [www.hrsdc.gc.ca](http://www.hrsdc.gc.ca))

<sup>100</sup> Canada Revenue Agency, *Canada Child Benefits*, July 2007 – June 2008, p. 7.





The applicant must be a resident of Canada for taxation purposes, and either the applicant or their spouse/ common law partner must be a Canadian citizen.

The amount of the benefit (for 2007/2008) is calculated on:

- the number of children the applicant has;
- the applicant's province or territory of residence;
- the applicant family's net income; and
- the applicant's eligibility for the disability amount.

The basic CCTB benefit is CAN\$106.91 per month for each child under 18 years of age. The NCBS provides a further CAN\$165.66 per month for the first child, CAN\$146.50 per month for the second child, and CAN\$139.41 per month for each additional child. The NCBS is available to low income families and is means tested.

Recipients of this benefit are also eligible to receive the 'Family Supplement' if their family's net income does not exceed CAN\$25,921 per year. The Supplement is a maximum payment of 80% of the recipient's average insurable earnings, and is dependent on the number of children in the family and their ages.

#### **Child Disability Benefit<sup>101</sup>**

The Child Disability Benefit (CDB) is an additional monthly benefit paid with the CCTB, which provides financial assistance to qualified families caring for children with severe and prolonged disabilities. The CDB is based on family net income and provides up to a maximum monthly payment of CAN\$191.66 per child to families with eligible children.

#### **Childcare expenses<sup>102</sup>**

An applicant, or their spouse, who has paid someone to look after their child (where the child is under 16 and has a mental or physical infirmity) will be eligible to deduct the childcare expenses on their tax return. The deduction is up to CAN\$4,000 for a child born in 1989 or earlier who has a mental or physical 'infirmity', and is dependent on the applicant or applicant's spouse/ common law partner, but who does not qualify for the "disability amount". For children who do qualify for the disability amount, the deduction is for expenses of up to CAN\$10,000.

#### **Amount for eligible dependent<sup>103</sup>**

A carer (who is not living with or supported by a spouse/common law partner) may be eligible to claim a tax deduction for a dependent who lived in the carer's home and whom the carer maintained. The dependent must be either:

- the carer's parent or grandparent by blood, marriage, common-law partnership or adoption; or
- the carer's child, grandchild, brother or sister, by blood, marriage common law partnership, or adoption and either under 18 years of age or mentally or physically infirm.

<sup>101</sup> Canada Revenue Agency, *Medical and Disability Related Information*, 2006, p. 20.

<sup>102</sup> Canada Revenue Agency, *Medical and Disability Related Information*, 2006, p. 20.

<sup>103</sup> Canada Revenue Agency, *General Income Tax and Benefit Guide*, 2006, p. 34.



The amount is tested against the dependent's net income. If the dependent's net income was CAN\$751 or less for the taxation year, the carer is eligible to claim a credit of CAN\$7,505. This credit is reduced (by reference to a scale) if the dependent's income was between CAN\$751 and CAN\$8,256 for the taxation year. The carer is not eligible to claim this credit if their dependent's net income for the taxation year was CAN\$8,256 or more.

#### **Amount for infirm dependents aged 18 years or over**<sup>104</sup>

A carer can claim an amount for each adult dependent provided the following conditions are met. The dependent must be:

- the carer's (or carer's spouse/common law partner's) parent, grandparent, brother, sister, aunt, uncle, niece or nephew; and
- born in 1988 or earlier; and
- mentally or physically 'infirm'; and
- dependent on the carer, or on the carer and others, for support; and
- a resident of Canada at any time in the year.

This credit may be claimed in addition to the 'amount for eligible dependent' (above), but cannot be claimed in addition to the 'caregiver amount' (below).

This credit is tested and calculated against the dependent's net income. A carer is not eligible to claim this credit unless the dependent's net income was less than CAN\$9,513 for the relevant taxation year.

The maximum amount claimable is CAN\$3,933 minus the credit that the carer obtained under the amount for infirm dependents aged 18 years or over.

#### **Caregiver amount**<sup>105</sup>

A carer who maintained a home where he or she and a dependent lived may be eligible to claim a caregiver amount on their tax return. The caregiver amount is a tax credit to the maximum amount of CAN\$3,933.

To be eligible, the dependent must be:

- the carer's (or carer's spouse/common law partner's) child or grandchild; or
- the carer's (or carer's spouse/common law partner's) brother, sister, niece, nephew, aunt, uncle, parent or grandparent; and
- a resident of Canada.

In addition, the dependent must have been:

- 18 years of age or older when he or she lived with the carer; and
- dependent on the carer due to a mental or physical 'infirmity', or, if he or she is the carer's (or carer's spouse/common law partner's) parent or grandparent born in 1941 or earlier.

<sup>104</sup> Canada Revenue Agency, *General Income Tax and Benefit Guide*, 2006, p. 35.

<sup>105</sup> Canada Revenue Agency, *General Income Tax and Benefit Guide*, 2006, p. 37.



The dependent's net income must have also been less than CAN\$17,363. The caregiver amount must not be claimed in addition to the amount for infirm dependents.

#### **Disability Amount transferred from a dependent<sup>106</sup>**

The "Disability Amount" is a tax credit that reduces the amount of income tax that an eligible person with a disability has to pay. For people with a disability aged 18 or older, the Federal Disability Amount for the year of 2006 was CAN\$6,741. A supplement is available for people with a disability who are aged under 18 years.

A carer may be able to claim all or part of their dependent's 'Disability Amount' if the dependent is a resident of Canada and depends on the carer for 'support' (defined by the Canada Revenue Agency as 'some or all of the basic necessities of life such as food, shelter and clothing').

In addition, one of the following situations must apply to the carer:

- (1) the carer claimed the 'Amount for Eligible Dependent'; or
- (2) the dependent was the carer's (or carer's spouse's/common law partner's) child, grandchild, parent, grandparent, brother, sister, aunt, uncle, niece or nephew and the carer claimed the 'Amount for Infirm Dependents Age 18 or Older' or the 'Caregiver Amount' for that dependent, or could have if the dependent had no income and had been 18 years or older in the relevant taxation year.

## **4.4 JAPAN**

### **4.4.1 Legislation**

#### **Law concerning the welfare of workers who take care of children or other family members including childcare and family care leave 1991 (Japan)<sup>107</sup>**

The Law has the principle objective, as defined in article 3, of enabling workers to engage in a full working life by making effective use of their abilities, and to fulfil their roles as family members with regard to caring. Carers are provided with several protections under the law as follows:

##### *1. Family care leave*

Chapter III of the Law (articles 11-15) provides workers with a right to take family care leave for a family member requiring constant care for two weeks or more due to sickness, injury or physical or mental disability.

Article 2 of the Law defines 'family member' as a spouse, parent, child, or parent of a spouse. It also includes the worker's grandparents, siblings and grandchildren who co-reside with and are dependent on the worker.<sup>108</sup>

'Spouse' is defined in article 2 to include a person in a relationship with the worker that is factually similar to marriage, notwithstanding the fact that no marriage has been registered.

<sup>106</sup> Canada Revenue Agency, *Medical and Disability Related Information*, 2006, p. 22.

<sup>107</sup> Available at [http://www.jiwe.or.jp/english/law/law4\\_1\\_3.html](http://www.jiwe.or.jp/english/law/law4_1_3.html)

<sup>108</sup> *Enforcement Regulations for the Law Concerning the Welfare of Workers Who Take Care of Children or Other Family Members, Including Child Care and Family Care Leave (Japan)* article 22.



Article 15 provides that the period of leave must not exceed 93 days (three months) and can only be taken once for each family member. Article 12 provides that that an employer may not refuse an application for family care leave. However, in some cases where there is a workplace collective agreement, the employer is permitted to refuse the application.<sup>109</sup>

### 2. Limitation on extension of working hours (limit on overtime)

Chapter IV of the Law (particularly article 18) provides that if a worker who takes care of a family member in need of care (as defined above) so requests, an employer must limit the worker's overtime to 24 hours per month and 150 hours per year.

However, article 17 provides an exception where the worker's request would impede normal business operations.

### 3. Limitation on night work

Chapter V of the Law (articles 19 and 20) provides that if a worker who takes care of a family member in need of care (as defined above) so requests, the employer must not make the worker work in the period between the hours of 10pm and 5am (night work). The request must be limited to a period of one month or more and six months or less.

Article 19 provides the employer with an exception to the Law where the request to avoid night work would impede normal business operations or where the worker's continuous term of employment has been less than one year.

## 4.4.2 Benefits and Allowances

### Family care leave benefit<sup>110</sup>

Where Family care leave has been taken by a worker in accordance with the above specifications, the *Employment Insurance Law 1974* (Japan) provides that the worker is entitled to the Family care leave benefit (Benefit).<sup>111</sup> The worker must, however, have been insured for a period of not less than 12 months preceding the claim.

The payment of the Benefit is limited to one period of three months leave.<sup>112</sup> The amount of the Benefit for a single payment unit period is 40% of the amount obtained by multiplying the worker's average daily wage by 30.<sup>113</sup> The worker's average daily wage can be calculated by dividing the wages paid to the worker over the last six months by 180.<sup>114</sup>

<sup>109</sup> International Labour Organisation, *Child Care and Family Care Leave Law – Japan*, [www.ilo.org/public/english/employment/gems/eeo/law/japan/care.htm](http://www.ilo.org/public/english/employment/gems/eeo/law/japan/care.htm); *Child Care and Family Care Leave Ordinance* (Japan) articles 1, 2, and 23.

<sup>110</sup> Under the *Employment Insurance Law* (Japan), Law No 116 of December 28, 1974.

<sup>111</sup> *Employment Insurance Law* (Japan), Law No 116 of December 28, 1974, article 61-7.

<sup>112</sup> *Employment Insurance Law* (Japan), Law No 116 of December 28, 1974, article 61-7-3.

<sup>113</sup> *Employment Insurance Law* (Japan), Law No 116 of December 28, 1974, article 61-7-4

<sup>114</sup> *Employment Insurance Law* (Japan), Law No 116 of December 28, 1974, article 17



The National Treasury is the department, which bears the expense of this benefit.<sup>115</sup>

### **Special child rearing allowance<sup>116</sup>**

A monthly allowance is provided to individuals (mother, father or guardian) caring for a child who has a physical or mental disability, until the child turns twenty years of age. The amount of the monthly allowance (as of 2004) is ¥50,900 for first degree ('severe') cases and ¥33,900 for second degree ('intermediate') cases, depending on the severity of the child's disability.

To be eligible for the allowance, the child must not be enrolled in a caring facility and must not receive a public pension due to their disability. Both the child and the applicant must be living in Japan.

The allowance is income-tested against the applicant's income, and against the legal family supporter/spouse's income, taking into account the number of dependents living in the household. For example, if the applicant has one dependent in the household, the income cap (as of 2004) is ¥4,976,000 for the applicant, and ¥6,537,000 for the legal family supporter/spouse.<sup>117</sup>

### **Child-rearing allowance (disabled allowance)<sup>118</sup>**

This allowance is distributed to the single parent or guardian of a child who is under the age of twenty and who has a moderate physical disability. The allowance is provided to contribute to the stability and independence of the household in which the child is raised.

The allowance is not payable where the child has been placed in a home, childcare institution or facility, or where the child's parents are married or can be considered to be married.

The monthly allowance amount for 2007 is ¥15,500 for each child. The allowance is tested against the applicant's income, taking into account the number of dependents in the household. For example, in households where the applicant has one dependent, the income cap (after income deductions or expenses) is ¥3,984,000.<sup>119</sup>

### **Indirect benefits**

In addition to the above allowances, the carer may be indirectly assisted by the Welfare allowance for children with disabilities (welfare allowance), or the Special allowance for persons with a disability (special allowance).

The welfare allowance is provided to individuals under 20 years of age who require special care and attention on a constant basis due to severe physical or intellectual disabilities. The monthly allowance as of 2004 is ¥14,430. The

<sup>115</sup> *Employment Insurance Law* (Japan), Law No 116 of December 28, 1974, article 66

<sup>116</sup> *Special Child Rearing Allowance Law* (Japan), Law No 134 of 1964, extracted in Japan International Cooperation Agency, *The 38 Selected Japanese Laws Related to Persons with Disabilities*, 2004.

<sup>117</sup> Child and Family Information Station [http://www.city.sendai.jp/kenkou/kodomo/kodomo/english/kyuufu/kvuufu\\_3.html](http://www.city.sendai.jp/kenkou/kodomo/kodomo/english/kyuufu/kvuufu_3.html)

<sup>118</sup> *Child Rearing Allowance Law* (Japan), Law No 238 of 1961, extracted in Japan International Cooperation Agency, *The*

*38 Selected Japanese Laws Related to Persons with Disabilities*, 2004.

<sup>119</sup> Monthly Meguro, June 2007, <http://www.city.meguro.tokyo.jp/english/monthly/0706/20070602.htm>



allowance is income tested against the income of a person with a disability, and the income cap as of 2004 is ¥5,180,000.<sup>120</sup>

The special allowance is provided to individuals 20 years of age or over who require special care and attention on a constant basis due to severe physical or intellectual disabilities. The monthly allowance as of 2004 is ¥26,520. The allowance is income tested against the income of the person with a disability, and the income cap as of 2004 is ¥5,180,000.<sup>121</sup>

## 4.5 THE NETHERLANDS

### 4.5.1 Legislation

The Netherlands does not have a specific Act that focuses on working carers. The most relevant legislation is: WMO - Wet Maatschappelijke Ondersteuning (Social Support Act).

This Act gives the person in need of care access to financial support. Yet this Act is also relevant to the person providing care as this is the funding model through which carers can be paid for their support.

Access to care is available through two funding models:

1. Paid Care – after the assessment of care needs, the Government pays for agency care directly (the transaction is directly between agency providing care and Government)
2. Personal Budget (PGB) – people who need care can choose on an individual basis how to spend the money they are entitled to (there is an assessment body through WMO that determines what level of care is needed). Through this model the person in need of care can choose to pay their family members or friend who is providing care. The volunteer carer (whether employed or not) can be paid through the Personal Budget.

### 4.5.2 Allowances

There are no Government based allowances except for the PGB (PGB) that enables the care receiver to pay the caregiver for their contribution.

### 4.5.3 Taxation Benefits

There are no tax allowances available for working carers.

### 4.5.4 Government policies

As mentioned before, The Netherlands does not have a specific Act that focuses on working carers, however the Dutch government has developed certain policies to support the working carer.

Since 2001 the Dutch Government has acknowledged the importance of the working carer to be part of society, meaning they see a working carer as

<sup>120</sup> Special Child Rearing Allowance Law (Japan), Law No 134 of 1964, extracted in Japan International Cooperation Agency, *The 38 Selected Japanese Laws Related to Persons with Disabilities*, 2004.

<sup>121</sup> Special Child Rearing Allowance Law (Japan), Law No 134 of 1964, extracted in Japan International Cooperation Agency, *The 38 Selected Japanese Laws Related to Persons with Disabilities*, 2004.



someone who has to juggle tasks and who therefore needs to be supported. The Government acknowledges the key principle that a citizen should have the right to work and care at the same time. Just like working parents – working carers can therefore access existing regulations via the Work and Care Act (SZW 2001).

Relevant Regulations come from 3 different areas, namely:

- Provision of Services for Care (Zorg en dienstverlening)
- Work Related Support Scheme (Werkgerelateerde steun)
- Financial Support (Financiële steun).

#### **4.5.6 Provision of Services for Care (Zorg en dienstverlening)**

Taking the work commitments of the carer into consideration at assessment stage: There is no specific assessment body for carers (such as in the UK and Finland), however the carer comes into view via the person in need of care.

Respite Care – this is a method the Dutch Government sees as a way to support working carers by temporarily yet completely taking over the care tasks to give the working carer a break. Access to respite care is individually assessed and is fully dependent on the client who requests care. This means that respite care is not always accessible and will depend on individual case assessment.

Timetable Projects supported by the ESF (European Social Fund) - some of the projects run by this body are focusing on supporting the working carer.

ICT and care at home – recently the Dutch Government has demonstrated an interest in further exploring the role IT can play to support the working carer. ICT offers the carer the flexibility to work and learn (e-learning) from home. The Government has also considered the role ICT can play with respect to people who share care – a website called sharecare.nl offers a platform where people can share info and hand-over important information on the person in need of care.

#### **4.5.7 Work related support scheme (Werkgerelateerde steun)**

##### **1. Flexibility**

*Work and Care Act* (2001) provides that all employees who have worked with the employer organisation for over a year have the right to ask for a flexible work arrangement that fits their personal circumstances. Employers are obliged to handle the request in fairness however they do have the right to reject the request when the overall interest of the business is in danger. In 2001 a survey showed that 50% of all requests were honored. In smaller organisations these were often informal arrangements.

##### **2. Leave arrangements and entitlements to work part-time**

*Work and Care Act* (2001) offers all employees the right to short carers' leave and/or calamity leave. Specifically for those carers looking after a long-term/critically ill person there are entitlements of 6 weeks full-time or 12 weeks part-time carers leave. However only the calamity leave is paid for. Other leave arrangements can be financed through the career history records



“levensloopregeling” where employees can save money or annual leave days to use for sabbatical, education, care responsibilities or early retirement.

### 3. Financial Compensation

The Netherlands does not offer a carers allowance directly to the working carer to support those carers who are forced to work fewer hours or stop altogether to care for their direct family or relative.

In the Netherlands working carers can indirectly access financial support via the person who applies for care. The person applying for care can indicate that they want to access a ‘pgb’ a “Personal Budget” and through this personal budget they can pay for the care offered by the working carer. The compensation is relatively high Euro 15.50 per hour (versus 2 Euro’s per hour carer allowance in UK).

The Dutch Government recognizes that via the pgb, the volunteer carer replaces a professional carer. The UK Carer Allowance on the other hand is more based on social welfare as only people in low income groups and who write lots of care hours a week are entitled to carers allowance.

### 4. Exemption of the obligation to apply for jobs

### 5. The right to use your carers’ responsibilities as work experience on your resume.