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Women and Informal Caregiving

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Women and Informal Caregiving
(Gender Impact Assessment No. 7)

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1. Introduction

In our community, women are the predominant providers of informal care for family members and friends, including children with special needs, frail older people and people with disabilities, mental illness, chronic condition or terminal illness¹. According to the Australian Institute of Health and Welfare, caring is defined as giving 'assistance and support in response to a need arising in the family or community' and primary caring as providing the *majority* of care for an ongoing period². In 2003, the Australian Bureau of Statistics' (ABS) Survey on Disability, Ageing and Carers found that women accounted for 71 percent of primary carers of older people and people with disabilities¹.

Informal care does not involve payment or government regulation, as distinct from formal care which is paid and/or regulated¹. Informal care is predominantly provided by family, friends or community networks³, and mostly by women aged between 35 and 64 years¹. Care in this context includes, but is not limited to, providing emotional and/or social support, personal care, 'minding', housework and meals, shopping and errands, transport, accommodation, financial support, medical assistance and legal aid⁴. It is important to note that most government bodies and non-government organisations do not include parental care of children, except in cases of special need such as disability, in discussion and statistics on informal care, but do include non-parental child-care, such as that provided by grandparents. While Women's Health Victoria (WHV) acknowledges that this is an omission in the literature on informal care, especially in the context of care provided by women, this narrowed definition will be used in this paper to avoid confusion. However, WHV contends that reframing the definition of informal care to include parental care is an issue worthy of debate.

The importance of informal caregiving to the overall provision of care in Australia is well documented. Due to the deinstitutionalisation of care services and the desire by many to be cared for at home, much of the necessary care is carried out by informal carers in the community². Carers Australia estimates that informal care accounts for 75 percent of care for older people and people with disabilities nationally⁵. Informal care has thus been described as 'the submerged portion of the "iceberg of welfare"' and 'the most important supplier of long-term care in Australia's welfare system'⁶. According to the ABS, in 2003 16.2 percent of the Australian population was acting as an informal carer in either a primary or minor role for an older person and/or person with disabilities⁷. A 2005 report by Access Economics, *The Economic Value of Informal Care*, estimated that the opportunity cost of informal care of older people and people with disabilities, measured as the reduction in paid employment due to caring, amounted to \$4.876 billion (approximately 0.6 percent of GDP) and the replacement cost, i.e. the cost of providing the same services through formal care, was \$30.548 billion (3.5 percent of GDP). Other estimates suggest that the amount of informal care currently occurring in the community is equivalent to one million full-time positions⁸.

2. The issue

Two of the most significant factors affecting provision of informal care in Australia are the ageing population and the shift towards the deinstitutionalisation of care.

A reduction in the birth rate and concomitant rise in life expectancy is increasing both the

number of older people in the community and their share of the total population². As the 'baby-boomers' reach old age in the years between 2020 and 2030, this group will be in greater need of assistance and care services². Carers Australia predicts that this rise in the number of people potentially in need of care will not be mirrored by an equivalent increase in the number of carers willing and able to take on informal care responsibilities⁹. Other research commissioned by the Myer Foundation suggests that the pool of informal carers is shrinking as the population ages¹⁰. This projected disparity raises concerns about how the current supply of informal carers will be sustained in the future. The Myer Foundation study found that within three decades, people aged over 65 years will constitute over 50 percent of the total number of voluntary carers in society and of that number two thirds will be women¹¹.

In addition, the number of women in the workforce, increased rates of relationship breakdown and the tendency towards smaller families has influenced availability of, and pressure on, informal carers². Changing patterns of childbearing has also impacted on the provision of informal care. Research indicates that many women are having children in their mid to late thirties, increasing the possibility that caring for their children and a parent(s) or friend may coincide⁹. Women caring for dependent children and older family members simultaneously are often referred to as 'sandwich generation' women⁴. According to the AIHW, in 2003 approximately one in four women of reproductive age were predicted to remain childless meaning they will not have children to potentially assume responsibility for their informal care needs².

The need for informal care has also been substantially increased by the deinstitutionalisation of care services that has occurred over the last two decades, particularly services for older people, children in out-of-home care, people with disabilities and people with mental health problems². This shift has both increased the need for unpaid care and been underpinned by the contribution of informal carers in the community. The benefits for those in need of care, such as being able to stay in their homes, and for the community as a whole, including the cost saving of a reduction of formal care services, have been made possible by the contribution, and often sacrifice, made by carers, predominantly women. However, informal care does not suit all situations and, as will be discussed, can have considerable negative impacts for the carers themselves. There is therefore a continued need for sufficient and affordable formal care options to be made available².

3. Women and informal caregiving

As already stated, women take on the majority of informal caregiving in Australia. Despite women's increased access to, and need to participate in, paid employment, the expectation that women will be the caregivers in addition to, or instead of, paid work remains. Sociologist Michael Bittman and colleagues suggest that 'gender roles virtually dictate women's responsibility for care'⁶. For instance, women carers are less likely than men to utilise respite services¹⁶ which can perhaps be attributed to the societal expectation that women should take on and accept caring responsibilities as part of a stereotypical 'woman's role'. As a consequence, women may experience disapproval if they show resistance to the role of caring or show that they are unable to cope.

There are also gender differences in the tasks undertaken by women and men in the informal

care context, with women often taking on the overall coordination of care⁶. Bittman and colleagues also argue that 'women play a greater role than men in helping with personal and daily tasks, while men (except for spouses) more often undertake occasional help, such as doing repairs, putting together items like furniture, or installing equipment in the home'⁶.

3.1 Health and wellbeing impacts on carers

It is widely acknowledged that there can be many positive aspects of the informal caring role for carers. For instance, the ABS has found that one in three primary carers believed the caring role strengthened their relationship with the person they were caring for².

However, carers also report many negative health and wellbeing impacts associated with caring. For instance, the 2003 ABS Survey on Disability, Ageing and Carers¹ found that:

- nearly three quarters of carers reported feeling dissatisfied with their caring role (compared to 25.7 percent who felt satisfied),
- 29 percent felt that their wellbeing had been adversely affected by their caring role,
- 72.4 percent of primary carers experienced some form of physical or emotional negative effect from providing care,
- over one in four (26 percent) women carers reported fair to poor health compared to 12 percent of women generally
- 44.5 percent had their sleep interrupted; for nearly half of whom interruption was frequent,
- 33.7 percent felt weary or lacking in energy,
- 29.2 percent felt worried or depressed and
- over 10 percent of primary carers have a stress-related illness¹².

Clinical studies have also found higher rates of depression in caregivers than in control populations.

In the Health Report 2003, President of Carers Australia Louise Gilmore highlighted that many carers can be poor in financial terms, however, they also can be deprived in terms of social contacts and a life separate to their caring role¹³. Caring can take a toll on carers' personal relationships, with 22 percent stating that their relationship with the care recipient had become strained since care commenced and nearly one quarter reporting having lost or losing touch with friends due to care responsibilities². The negative impact on carers' relationships and social networks due to their reduced ability to participate in activities outside their caring role can lead to carers experiencing social isolation, which in turn can impact on their psychological wellbeing⁶. Social isolation has been linked to poor mental and physical health and wellbeing, including depression, lowered immune system and increased likelihood of heart disease¹⁴. Studies have demonstrated that women are more vulnerable than men to the effects of reduced social support¹⁵. Social connectedness provides people with support, a sense they belong and have a role to play in society and contributes to feelings of happiness and contentment. Relationships and networks also give people vital avenues of support during difficult times and are therefore particularly vital for carers.

Respite care is therefore an important service that enables carers to have a break from

caring and to maintain a high quality of care. A 2004 report by the Victorian Department of Human Services, *What Carers Value*, found that access to respite and support services increased carers' quality of life⁵. However, a recent Australian study found that 88.6 percent of informal carers had never used respite services and that, controlling for other variables, women carers were less likely to use respite services than men¹⁶. Factors contributing to carer's non-use of services included carer's lack of understanding of respite care, passivity towards respite care, negativity towards mental health services, the care recipient's attitude towards respite care, narrowness of the service's focus, lack of flexibility and inadequate availability or accessibility of respite care and related services. Carers may also be choosing not to access respite services for personal reasons, including guilt or financial constraints. This study also found that use of respite services increased with the age of the carer, suggesting that as the caring population in Australia ages so too will the need for formal support services.

Other physical health impacts of caring are musculoskeletal injuries resulting from incorrect lifting, lowering, carrying or moving of the care recipient or care-related equipment¹⁷.

With women taking on the majority of informal care, particularly as primary carers, it follows that these health and wellbeing costs are predominately shouldered by women.

3.2 Workforce participation

Informal caregiving often has considerable impacts on women carers' ability to fully participate in paid work. Significantly, the peak age group within which women are taking on the role of carer (35-64 years) is also time women could be participating in the workforce. As a result of their caring responsibilities women are often compelled to work fewer hours, choose jobs primarily for their flexibility rather than job satisfaction or not work at all¹⁸. This, in turn, can undermine carers' career prospects and development⁸. A report commissioned by Carers Australia and conducted by Commonwealth Financial Planning found that 'over half of female primary carers aged 30 to 64 years are not in the paid labour force compared to less than a third of other women in the same age group' and that 'of those women who do work, primary carers spend fewer hours in paid employment than do other women'¹⁸. A 2007 report by the Taskforce on Care Costs found that informal carers of older people or people with disabilities are 'much less likely [than non-carers] to participate in the paid workforce, and at a level commensurate with their skills and qualifications'¹⁹.

Women's participation in the workforce is also more greatly affected by their caring roles than men's⁷, with women more likely to make adjustments to their paid employment to accommodate their caregiving responsibilities⁶. A 2008 report by the Centre of Full Employment and Equity suggests that this is underpinned by the 'breadwinner model' whereby gender roles dictate that men have a greater commitment to work⁷. As the responsibilities of a carer increase, their ability to participate in the workforce decreases. Carer's involvement in the workforce is also highly dependent on the provision of respite care and flexible workplace arrangements⁷. In order for carers to juggle their family and work commitments many women use childcare or other informal carers. Some women caregivers still need to be employed part-time for financial reasons and others are concerned that staying out of the work force will potentially make it difficult to re-enter⁵.

While women may care for young children and or family members throughout most of their lives, there is evidence to suggest that men tend to take on the care provider role at older ages: '22 percent of men aged 75 or over were carers and 5 percent of men in this age group were primary carers'². As a result of men's tendency to assume the caring role at a later age, they are more likely to be in full-time employment throughout their working life and, therefore, be in a better financial position by the time they retire.

3.3 Financial implications

The deinstitutionalisation of care has meant that the cost to the public has been reduced whilst the cost to individuals has increased²⁰. The expense to individual carers often includes the everyday care costs, as well as the cost of treating physical and mental ill-health associated with caregiving¹². A 2004 study commissioned by the Victorian Department of Human Services found that over half of full-time carers stated that their income was less than \$200 a week and that carers are often forced to use savings or superannuation, cut back on basic living costs or borrow money to support their care role⁵.

Informal care can also have considerable financial implications for carers as a result of lost or reduced employment opportunities and, in turn, diminished financial security, superannuation and retirement savings and increased risk of poverty⁶. This is partly reflected in the current difference in women's superannuation payouts compared to men's (\$31,000 compared to \$110,000)²¹. In turn, carers themselves will be less likely to be able to afford costly residential and/or care facilities should they need them in the future, which will be an additional factor contributing to increased demand for informal care in years to come.

It is also important to note that the original decision to utilise informal rather than formal care is often substantially influenced by the high financial costs associated with residential and care facilities⁵.

4. Policy context and challenges

Recognition of Australia's ageing population has led to a revision of policy on caregiving and increased government and NGO attention on the future of caring in the community²². In 2006, the Victorian Department of Human Services (DHS) released a whole of department policy framework, *Recognising and supporting care relationships*, to guide their work related to informal care. This overall policy framework is implemented through three action plans targeting specific DHS program areas, including mental health, disability and older people. These action plans are:

- *Recognising and supporting care relationships for older Victorians*
- *Caring together – An action plan for carer involvement in Victorian public mental health services*
- *Disability Services Carer Action Plan: Recognising and supporting care relationships*

Given the gendered nature of informal caregiving, it is important to analyse policy frameworks in terms of their awareness of the relationship between gender and informal

care. Analysis of the DHS policy framework establishes that the framework is clearly underpinned by an understanding of the gendered distribution of informal caregiving. In discussion of the demographics of caring, the framework includes recognition that women make up the majority of primary carers, that caring is often represented and understood as 'women's work' and that women may be pressured into taking on the caring role²². However, while the framework acknowledges that policies which increase community care may have a greater impact on women than men, when examining the 'impact of caring' the different and greater impact on women is not discussed²². This omission is particularly problematic as the key principles of the framework, and in turn the action plans, focus on recognising, respecting and supporting carers and encouraging them to participate in support services. WHV contends that the uneven impacts of informal care on women must be central to the policy framework for these principles to be meaningfully incorporated into the funding and program delivery of care services in Victoria.

While the overall framework does include some recognition of the gendered distribution of informal care, the resulting action plans are largely gender blind. The action plans are the 'link' between the overall policy framework and the initiatives and programs which aims to assist carers in the community. Not recognising and explicitly addressing the gendered nature of informal care in these action plans is likely to undermine their effectiveness and the effectiveness of resulting programs and initiatives. Again, WHV recommends that all policy documents should reflect women's greater contribution to informal care and the greater negative impacts on their employment opportunities, financial security and health and wellbeing.

Other Victorian government policy documents that address informal caring include the *State Disability Plan 2002-2012*, *Wellness Guide - addressing carers' needs*, and *The Strengthening Palliative Care: A Policy for Health and Community Care Providers 2004-09*. An analysis of these documents indicates that they are also gender blind.

Carers Victoria and Carers Australia are the peak advocacy bodies representing the needs and interests of carers in Victoria and nation-wide. Working together closely, they provide support, information and educational resources for carers and conduct community awareness, research and pilot projects on informal caring. In 2008, Carers Australia co-commissioned a report into the financial and health impacts of caring on women carers. As stated previously, the report reiterated that caring has a lifetime impact on women carers' health and financial security¹⁸. However, the website and majority of resources, publications and policy documents contain little to no gender analysis. For example, the *Key Issues For Carers* page of the website does not acknowledge the particular impact of informal caring on women. While anecdotal evidence used in some discussion papers includes gender-specific pronouns ('she'), the discussion does not demonstrate a gendered analysis²³.

WHV suggests that as the peak body, and one that is particularly focused on representing the *needs* of carers, it is important that Carers Victoria and Carers Australia incorporate gender into all their publications, resources, advocacy and public awareness work.

WHV appeals to the Victorian Government to develop and implement gendered caring policies. Many Australians are responsible for caring in our community however women take

on the majority of informal caregiving and, in turn, shoulder most of the negative impacts. Government policy should reflect this fact and services should be organised and provided accordingly in order to support Australia's caregivers and work towards a more fair and equitable system of care.

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