



Submission to the
House of Representatives
Standing Committee on Ageing

**Inquiry into Long Term Strategies to Address the
Ageing of the Australian Population**

Terms of Reference

The House of Representatives Standing Committee on Ageing will inquire into and report on long term strategies to address the ageing of the Australian population over the next 40 years.

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Executive Summary

The House of Representatives Inquiry into long term strategies for Australia's ageing population, provides Carers Australia with the opportunity to highlight the important and vital role of carers in caring for the aged and the issues that will confront them in meeting their caring responsibilities.

Governments and policy makers are vitally aware of the demographic trends that mean we can expect 25 per cent of the population to be aged over 65 years in 50 years time and are developing measures to accommodate this. With unpaid family and other informal carers as the cornerstone of the community care sector, providing the bulk of care to people with disabilities and frail older people, the role of carers will be critical in long term strategic planning.

While there is reliable data that indicates the trends in the ageing population, there is no such data on the likely availability of carers. However, a study in UK, workforce projections in Australia, and other factors such as changing family structures, suggest that people of workforce age may not be able to or willing to accept or fulfil their caring responsibilities.

Carers Australia believes caring is a personal, social and public responsibility shared by individuals, families, business, community organisations, public institutions and all levels of government. Carers Australia also believes that informal care in the community care sector will continue to be the foundation of care for people with disabilities and frail older people. As such there are a range of issues that impact on carers that need to be addressed in the short term if we are to encourage and support carers over the long term.

These issues include:

- greater recognition of the role of carers and their needs in policy making, health and welfare service delivery and the workforce
- a major refocussing of the community care sector to better integrate, re-align and adequately resource services
- improving and resourcing current programs within the community care sector such as in-home services, respite care, counselling and education for carers
- recognising the responsibilities of carers in the workforce and providing greater flexibility in the workplace.
- giving consideration to the circumstances and needs of carers in regard to retirement incomes and superannuation policy
- ensuring that social security supports carers in need and provides sufficient income to meet their needs.

Carers Australia makes the following recommendations to the House of Representatives Standing Committee on Ageing to promote the long-term sustainability of informal caring within the community care sector.

Recommendations

That the Government give explicit recognition to the needs of carers in its family, workplace, health and welfare policies with appropriate strategies and actions. This would re-integrate family caring responsibilities as a normal part of life, with the caring role recognised as only one of the many roles in which individuals are involved.

That consideration be given to adopting the UK carers model to recognise the needs of carers in Australia, with appropriate legislation and supporting strategies.

That the Government demonstrate its genuine commitment to progressing national Community Care by investing in the Community Care Program and ensure that new measures are well resourced and improve the capacity of carers to sustain their caring responsibilities alongside other vital responsibilities, including employment.

CA expects in-home support services, respite care, counselling and education for carers, and quality residential care to be ongoing, long term features of community care and caring for the aged. To ensure carers receive the support they need for their care to be sustainable, these services need to be readily available, affordable, flexible in their delivery and of a high quality. Therefore these services must be monitored closely and resourced sufficiently to ensure that a quality service is delivered and demand is fully met.

That the Government work with other employers to develop, promote and implement carer friendly employment policies that are mutually beneficial to the employee and employer.

That particular consideration be given to the circumstances and needs of carers in developing retirement incomes policy and superannuation regulation.

That the Government work with Carers Australia to develop a more equitable and adequate system of income support that:

- *acknowledges and assesses more fairly both the different levels of care requirements of the person in need of support and assistance and the full context of the caring situation.*
- *includes effective measures to offset the extra costs of care*
- *addresses the needs of carers living in rural and remote areas*
- *provides significant incentives and financial support for carers of workforce age to participate in education and employment and build their superannuation and retirement incomes.*

1. Introduction - Who we are

Carers Australia (CA) is the national peak body representing the 2.3 million carers in Australia. These carers, who are usually family members, provide unpaid care at home for children or adults who have a disability, mental illness, chronic condition or who are frail aged. Of these it is conservatively estimated there are 450,000 primary carers, including 125,300 primary carers providing help to persons aged 65 and over.

Our mission is to be the national voice of carers. Our vision is for an Australia which accepts its responsibilities for caring.

The members of CA are each of the eight state and territory Carers Associations, who have representatives on our Board.

CA represents the needs and interests of carers at the national level through:

- contributing to the Federal Government's policies and programs that impact on carers
- advocating for carers on needs and interests in the public arena
- networking and forming strategic alliances with other organisations to achieve positive outcomes for carers
- promoting information sharing and coordinating and facilitating joint work between the state organisations on matters of national significance.

We base our policies and evaluate others on the following six principles:

- caring is a personal, social and public responsibility shared by individuals, families, business, community organisations, public institutions and all levels of government
- carers are recognised and valued for their important contribution to the wellbeing of the Australian community and the people whom they support and for their unique expertise and skills in the caring role.
- carers are also recognised as individuals with their own needs within and beyond the caring situation.
- carers are entitled to the same rights, choices and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment and education.
- carers are included in decision making that relates to their care situation and impacts on their lives. Carers have a voice in legislation, policy and program development, service implementation and evaluation across all sectors.
- carers are able to access a wide range of information and resources, informal support and responsive, affordable services to complement caring. They are entitled to carer friendly policies and practices in other areas of their lives.

2. Aged people and informal care – the current situation

As a result of society's expectations and the policies of successive governments, the trend in the latter part of the 20th Century was away from institutionalised residential care to maintaining people in need of care, in their own homes. Unpaid carers are now the cornerstone of the community care sector and provide the largest proportion of care. Our society places a high value on this unpaid care as it preserves family structures and quality of life by allowing people to stay in their own homes surrounded by their family and friends. This is reflected in the Government's policy to assist people to live independently in their own homes and in their own community with access to community care when needed, wherever possible.

The statistics clearly show the trend away from institutionalised care to community care. In 1981, the level of residential provision was 111 places per 1,000 people aged 70 and over. In 2001 this had gradually dropped to 82 places per 1,000 people aged 70 and over.¹ Similarly, data analysed by the Australian Institute Health and Welfare from the 1993 and 1998 ABS Disability, Ageing and Carers Survey indicates a corresponding increase in the provision of services to people in their homes in the areas of self care, mobility, communication, housework, health care and meal preparation². This has largely been done through such programs as the Commonwealth and state funded Home and Community Care Program. These programs play an important role assisting the people in need of care, and also the carers who provide the bulk of the informal care needed.

Staying at home is very important for people who want to maintain their independence and dignity, but the ability to do so depends largely on the level of care needed and availability of informal care and supporting community care programs. This is evident from the ABS surveys on ageing, disabilities and carers.³

In 1998, there were 2.3 million people aged 65 and over, with the vast majority of these living in private dwellings (94 per cent). Of those in private dwellings 50 per cent had a disability. Forty six per cent of all older people needed assistance, with the need increasing with age. Of people aged 85 and more, 92 per cent needed assistance, compared with 32 per cent in the 65-74 age group.⁴

¹ Australian Institute of Health and Welfare, *Australia's Welfare 2001*, AIHW, Canberra, p. 115

² AIHW, p. 116

³ Commonwealth Gov, prepared by AIHW, *Older Australians at a Glance*, 1999

⁴ Australian Bureau of Statistics, *Disability, Ageing and Carers: Summary of Findings*, 1998

In the same survey it was found the vast bulk of assistance received by older people is provided by the informal care network. Among those receiving some assistance, 83 per cent received help from informal providers such as family, friends and neighbours, although 59 per cent received help from formal providers and 43 per cent received assistance from both informal and formal sources. The highest proportions receiving help from informal providers (at least 90 per cent) were those receiving assistance with personal care, mobility and communication, paperwork and transport.

In terms of availability and supply of carers providing informal care, in 1998, when the most recent ABS Survey of Disability, Ageing and Carers was done, the following were identified:

- a total of 2.3 million carers in Australia
- 450,900 primary carers⁵
- two thirds of primary carers were women
- 125,300 primary carers providing help to persons aged 65 and over
- 58 per cent of carers of older people were themselves over 65⁶
- 124,500 care receivers aged 65 and over with the primary carer living in the same household
- 76,500 care receivers aged 65 and over living elsewhere from the primary carer
- the average time spent per week providing primary care to people aged 65 and over with a disability was 43 hours.

These statistics illustrate the important role of unpaid family and other informal carers in the community care sector in providing care to the aged population in the Australian community today and the primary contribution they make to the management of care for the aged.

In financial terms the saving to the Australian economy of this unpaid work for adult care alone is conservatively estimated to be \$18.3 billion annually.⁷ Without carers, there would be much greater reliance on paid and other forms of care within and outside the home, which would, consequently, impose a substantial cost increase to the Federal Government and the taxpayer.

This is the situation as it stands today, however the purpose of this House of Representatives Standing Committee inquiry is to look at the strategies that will assist the ageing population in 40 years time. To do so, we first need to look at the ageing population projections and then look at what the likely demand for care will be and the likely supply of informal care.

⁵ The ABS defines a primary carer as a person of any age who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing for at least six months and be provided for one or more of the core activities of self care, mobility or communication.

⁶ AIHA, *Australia's Welfare 2001*, p. 205

⁷ AIHW, *Australia's Welfare 2001*, p. 17

3. The ageing population and informal carers – projections for the future

3.1 Projections on ageing

As the National Strategy for the Ageing has highlighted, the demographics of the Australian population are changing. We are rapidly becoming an ageing population with the population aged 65 years and over growing at around one fifth the rate of the population aged between 15 and 64. In 20 years time, the population aged over 65 is projected to be growing at three times the rate of the population between 15 and 64.

It is expected that the proportion of the population aged over 65 years could rise from around 12 per cent today to 18 per cent by the year 2021 and reach 25 per cent in 50 years time.⁸

Through the National Strategy for the Ageing, the Government is looking at ways to ensure people are able to enjoy active and healthy lifestyles as they age through measures such as encouraging people to stay in the workforce longer, providing for their own retirement income and taking an active part in the community. However, the health and care of people with disabilities and frail older people is a key concern to policy makers and the community generally as, not only is the population ageing, there is also a steady upward trend in the disability rate.

Currently the rate of disability is 17 per cent of the total population, and has been steadily rising as people become more willing to identify themselves as having a disability. The rate of disability increases with age – four per cent of children aged 0-4 years have a disability compared to 84 per cent of people aged 85 and over.⁹ ABS estimates that the number of Australians with disabilities can be expected to increase over the next fifty years with the ageing of Australia's population. This is influenced by people generally living longer and acquiring disabilities as they age, as well as people with pre-existing disabilities living longer.

In an analysis of trends and growth estimates the Australian Institute of Health and Welfare (AIHW) estimate:

"based on the 1998 age- and sex-specific prevalence rates, between 2000 and 2006, the total number of people with a severe or profound core activity restriction can be expected to increase by 11.6 per cent. This overall growth is mainly attributable to the rapid increase in size of the age groups 45-64 and 65 and over. Thus the ageing of the working age population and aged population is expected to contribute strongly to the growth in number of people with a severe or profound core activity restriction."¹⁰

⁸ *National Strategy for an Ageing Australia*, Commonwealth of Australia, 2001

⁹ Commonwealth Disability Strategy

¹⁰ Australian Institute of Health and Welfare, *Disability and ageing: Australian population patterns and implications*, AIHW, 2000, p. 155.

3.2 Informal care for the ageing population

Care of frail older people and people with disabilities is also heavily dependent on informal care provided by family and friends as the main source of help in day to day activities. It would therefore be logical to expect that with an increasingly ageing population and increasing number of people with age related or early onset disabilities, there would be an increased demand for informal care and community care services.

While the role and current need for informal carers is well established, the question is will there be sufficient carers to fulfil the role as the population ages and the rate of disability increases and, secondly, what support will carers need. In order to obtain a better understanding of this, CA is currently exploring the feasibility of commissioning a detailed study to project the level and nature of informal care that will be needed in Australia, and the level and nature of informal care likely to be available in the medium to long term.

As the AIHW discussed in its analysis of trends of informal care,¹¹ demographic trends would suggest some possibilities:

- over the next 50 years there will be an increased number of people aged 45-65, and more than in the 65 years plus age bracket. As this is the age group where the majority of carers are now drawn from, an increased population may mean there are more carers to draw from.
- the life expectancy of males is increasing at a faster rate than females. This may mean that people will be married for longer and be cared for by their spouse.
- 58 per cent of carers of older people were themselves over 65,¹² and are predominantly spouses. It is expected that carers will continue to be drawn from this group who are themselves aged.

However, none of the above scenarios take into account factors such as workforce participation and opportunities for carers; family support structures with divorce and fewer children; women delaying having children and then having dual caring responsibilities; geographic location of family and the care recipient; the increase in the number of single people and single person households; and the availability of additional or complementary services. All of these factors can potentially impact on the number of carers available and their willingness and preparedness to accept their caring responsibilities.

¹¹ *ibid.* p. 181

¹² AIHA, *Australia's Welfare 2001*, p. 205

A recent study in Britain at the Thomas Coram Research Unit, found that despite increasing demand for informal care of the aged and children, changes in the population and in work patterns means that fewer people will be available to provide care.¹³ Few employees wanted to give up work to take on caring responsibilities. These employees were basing decisions on a combination of factors including financial considerations, health, job satisfaction and stress, as well as caring responsibilities. The study was done in three stages - it firstly looked at changes over the last twenty years in employment patterns at household level. Secondly, a postal survey was completed by over one thousand employees aged 50 or over and recent retirees, from one urban and one rural English local authority. Thirdly, in depth interviews were carried out with 22 carers and ten non-carers, to explore how other factors affected their decisions about paid work and informal care.

CA is not aware of any similar research work in Australia, but believes the findings of this research would also be relevant to our situation with similar population trends and economic and workforce structures.

For many people who are likely to have caring responsibilities, early retirement was not an option for financial reasons. Moreover, the study also found that few people wanted to give up work entirely and that there was a strong desire to achieve a balance between work and caring responsibilities. Anecdotally, CA believes this is also the case with carers in Australia.

Dowrick and McDonald, argue in their critique of the Government's Intergenerational Report,¹⁴ that we can expect higher participation rates of women in the workforce over the next 40 years as the level of education increases and opportunities and work satisfaction expands. "Only one quarter of the cohort of women now aged around fifty stayed on to the final years of high school education. Over the next few decades, they will be replaced in the working age population by young women of whom nearly four fifths have completed Year 12". In addition, women who are accustomed to working are more likely to want to continue to participate in the workforce and derive job satisfaction and increase their earnings for their own retirement. Dowrick and McDonald also consider that the labour force participation rate of men could also increase as they delay early retirement. Those reaching ages of 55-64 years in the future will be better educated; less likely to work in industries that are in decline and be better placed in the knowledge based economy; and will have had the experience of adjusting to job changes and ongoing training.

¹³ Mooney A, Stratham J with Simon A, *Informal Care and work after fifty*, Joseph Rowntree Foundation, 2002.

¹⁴ Dowrick S & McDonald P, *Comments on Intergenerational Report, 2002-03*, ANU, 2002

It is very difficult to predict accurately what the likely supply of carers will be with an ageing population. However, we do know what the concerns of carers are now and what needs to be addressed if caring is to be attractive and we are to encourage people to accept and fulfil their caring responsibilities and maintain their own wellbeing. We anticipate that informal care will continue to be the cornerstone and bulk of community care for the ageing population and therefore needs to be appropriately supported and resourced to make it sustainable for carers and the community care sector in the medium to long term.

The discussion of issues and recommendations in the next section of the paper, reflects the principles outlined in Section 1 which come from the understanding that caring is a part of every individual's life at some stage and is an every day part of family and community life and our economic and social activities.

4. Issues for carers

A study conducted in Victoria between 1991 and 1998 examined a wide range of factors affecting the wellbeing of family carers and the social norms of caregiving.¹⁵ This research was different to any other that has been conducted in Australia for several reasons:

- the aim was to address both emotional and physical aspects of carer wellbeing and to assess the subjective feelings of carers as well as the objective activities they are involved in
- the scale of the longitudinal research and the strength of its design enabled a breadth and depth of analyses not previously undertaken in Australia
- it included a comparison group of women with “usual family responsibilities”
- the research was wider in scope than any previous research.

The pertinent findings from this research, was that caregiving reduces the wellbeing of carers compared to non-carers, but the overall impact on wellbeing among carers varies significantly in accord with their personal, social, and economic resources. The analysis showed that those with strong personal and social networks and greater economic resources were better equipped to undertake caregiving roles and these resources provided a considerable buffer against the demands of caregiving. Those who had lower wellbeing had fewer resources to protect them against the demands of caregiving roles and had very limited options. Carers aged under 50 were more likely to experience very negative wellbeing, while nearly two thirds of those aged over 65 reported positive or very positive wellbeing.¹⁶ Women carers were twice as likely as men to have negative wellbeing.

These findings support national survey work that CA undertook in 1999.¹⁷ That survey found, as a result of providing care:

- well over half of all the carers had suffered a decline in physical health
- a third of all carers have been physically injured, and virtually none had received any financial compensation
- of those carers needing disability aids or equipment to assist in providing care, nearly 60 per cent did not have all they needed
- over 70 per cent of all carers felt they had low energy levels
- over half believed they had worse mental and emotional health overall
- nearly 60 per cent had experienced major negative effects on their life opportunities, especially for travel, pastimes and paid work.

¹⁵ Howe A and Schofield H, *Family Care for Frail Elders and Norms of Caregiver Well-Being at the Turn of the Twenty-First Century*, unpublished to date

¹⁶ Wellbeing was measured using an index by combining responses to 26 items in the four scales of wellbeing included in the survey, covering positive and negative affect, perceived adequacy of social support, life satisfaction and feelings of overload.

¹⁷ 1999 National Survey of Carer Health and Wellbeing, *Warning – Caring is a Health Hazard*, Carers Australia

The findings of these pieces of research and the anecdotal evidence CA receives paint a picture of a large portion of Australians who are very dedicated and committed to their work at considerable physical, emotional and financial cost to themselves. The key issues that arise from such research and have long term implications in caring for an ageing population are discussed below.

4.1 Recognition of caring

While, caring is a positive and rewarding experience, there are extra costs attached to it that impact on the individual's wellbeing, health, relationships and financial situation. Carers largely take on the caring role because of love, commitment and obligation to family members and close friends and, in doing so provide a valuable service to the individual, family and community. They also need recognition for the social and economic contribution they make. This point was well made in a research paper by Mitchell and Thompson on welfare reform and caring:

"Carers need to be seen as senior partners in the care economy, as the primary contributors to the management of care. This shift in perspective is as critical for carers themselves, as for other parts of the community. Dialogue and debate which places carers at the centre rather than at the periphery of care production is required to shift the focus towards the locus of care effort and outcome – that is, the carer and the person receiving the care.

At the same time, carers need to be conceived as equal citizens in the contribution to economic and social life rather than maternal beings associated with the realm of private relations only. Correspondingly, there is a need for thought and debate which locates care production as fundamental to economic activity."¹⁸

In judging the importance of caring and its social and economic value, the evidence should speak for itself: there are 2.3 million carers, providing the majority of community care valued conservatively at \$18.3 billion per year for adults alone. With ten per cent of the Australian population involved in caring, and one in five households, caring is part of the life cycle, an everyday activity for many, and will impact on most people at some stage of their lives. Those impacts will vary enormously depending on the circumstances of the individual and the support they receive.

¹⁸ Mitchell M and Thompson M, *Changing Conceptions of Informal Care in Australia*, Paper presented at the National Social Policy Conference, July 2001.

In order to give carers the recognition and support they need, as a community we must do more to develop a culture that values caring in realistic and meaningful ways, with more than just rhetoric. Caring has to be accommodated and supported as a normal everyday activity in the same way that parenting and child care is, and not just seen as a private matter that is managed within families. While carers are on the national agenda, in terms of community care programs and social security support, CA believes that a wider Commonwealth policy view and a wider understanding of the role is now essential through its family, workplace and health policies.

In the UK, the needs of carers are given explicit recognition in the Carers (Recognition and Services) Act 1995. This legislation means that relevant service providers must provide a needs assessment for individual carers and provide services as identified by the assessment. This aims to help carers obtain the practical help they need by clarifying their rights in law. In addition, the Blair Government has implemented a National Strategy for Carers to bring together a range of initiatives designed to address carers' concerns and give them support.

Recommendation

That the Government give explicit recognition to the needs of carers in its family, workplace, health and welfare policies with appropriate strategies and actions. This would re-integrate family caring responsibilities as a normal part of life, with the caring role recognised as only one of the many roles in which individuals are involved.

That consideration be given to adopting the UK carers model to recognise the needs of carers in Australia, with appropriate legislation and supporting strategies.

4.2 Community care policy development

The Minister for Ageing, The Hon. Kevin Andrews, recently asked stakeholder groups and his Department to put forward ideas for a new model for national community care. In response CA has taken a long term, strategic view and has recently submitted a policy paper, *A Vision for Carer Support in Community Care*, which presents the case for a broader policy view with a national "Community Care Australia" policy that:

- recognises family and other unpaid care as foundational to community care
- supports carers as "care partners" who exercise other important roles as well as caring
- reflects a strategic, systemic approach both within and across Community Care and other key policy areas and programs.

While the federal Government has demonstrated recognition of the importance of family carers in community care through their inclusion in the Home and Community Care target group and the establishment of the National Respite Carers Program, this approach fails to address the wider social context in which caring occurs.

CA's vision for community care, carer well-being and support would no longer be conceptualised narrowly in terms of an issue that could be addressed by specific support services which are then provided by as a parallel system or added extra to existing service structures.

The most appropriate framework for a model of Community Support Services is essentially a life cycle care model. This model identifies the age and life stage of the person in need of support, their carer and others in the family unit and the critical features that are present or emerging in the care situation. The life cycle model grounds service delivery in the reality of each particular care situation and the quality of life issues surrounding it, providing an essential basis for shared decision making about key aspects of services and assistance. The aim is to provide support services to foster independence for the person needing support (and their carer, where applicable) and to ensure that services are appropriately clustered and responsive to the specific needs of individual's stage of life.

The features of this system would be:

- simple, reliable and timely access to personalised information about services and assistance
- assessment of the care situation with 'core assessment information' valid across community care programs and services and reviewed regularly
- carer-directed and client-directed decision making
- affordable and flexible assistance, tailored to the needs of the family and the particular care situation
- quality services and programs, with national community care standards and appropriate quality assurance and accreditation processes.
- a range of support services for carers and people with disabilities.

In order to achieve this life cycle care system policy makers need to:

- consolidate programs under an inclusive national banner as "Community Care Australia
- define the target group for this suite of programs
- clarify and further develop the respective roles and functions of the Commonwealth Carer Resource Centres, Commonwealth Carer Respite Centres, Carelink and 1800 telephone information numbers
- renew Commonwealth/State and Territory funding responsibilities and rationalise their Community Care responsibilities, and establish a National Community Care Planning Framework and Planning and Resource Allocation Process
- develop a policy framework for "Community Care Australia"
- integrate key community care services into three broad levels of service
- introduce a "Community Care Australia" card to facilitate the integration of assessment information
- develop a national community care workforce education and training program to support the new direction of Community Care

- develop a 'road map' for "Community Care Australia" with key access points and pathways.

Research and anecdotal evidence demonstrate that carer wellbeing is negatively affected not only by demands of the caring role, but more importantly by the extent that caring impinges on the other roles, particularly paid employment and the opportunity to participate in other activities. Therefore the design and delivery of community services, such as day care programs, needs to enable carers to participate in employment by, for example, operating in regular business hours rather than school hours. Carers have identified lack of appropriate and flexible community services, such as these programs, as one of the major barriers to their workforce participation.

Community care development is inextricably linked with workplace flexibility and better income support, which are also discussed in this submission, as CA believes both these are essential for carers to better meet their caring responsibilities and maintain their quality of life.

Recommendation

That the Government demonstrate its genuine commitment to progressing national Community Care by investing in the Community Care Program and ensure that new measures are well resourced and improve the capacity of carers to sustain their caring responsibilities alongside other vital responsibilities, including employment.

4.3 Community Care and Carer Support Services— improving the current system

As a long term strategy, CA believes the community care sector should be reviewed with measures put in place for it to cope with the extra demands of an ageing population and better serve those in need as outlined in the above section. However, as an interim measure, much can be done to improve the current suite of assistance packages that are available to those in need and their carers.

As a member of the National Aged Care Alliance, CA believes quality community care is a critical factor in a positive experience of ageing for the 93 per cent of people over 65 years of age who live in the community and want the choice of remaining at home.

4.3a In-home support services

The current programs offering community care include Home and Community Care, Community Aged Care Packages and Extended Aged Care at Home Packages, which are critical to consumer choice and giving people the option of staying at home. In order for these programs to be effective and meet demand, they must be properly resourced, adequately staffed and better integrated with other aged care services.

Carers Australia believes recently increased HACC budget allocations fall short of addressing widespread demonstrated unmet needs. Previous budget cuts due to user charges being included as program growth should be restored and actual service delivery costs must be covered. CA:

- seeks an increase in HACC funding by 20 per cent as an initial injection to enable a more appropriate level of care to be offered to existing clients with six per cent indexation of the program to ensure continuing growth to meet demand and cover the delivery costs.
- acknowledges the additional 6,000 Community Aged Care Packages funded in the 2002-03 Budget, and recommends the demand and unmet need for such packages be monitored to ensure that funding and packages keep pace.
- recommends expanding the Extended Aged Care at Home program to enable more equitable access to this higher level of care.

4.3b Respite services

Respite care is vital for the wellbeing of the carer and the person in need of care to provide a break for the carer and provide a positive experience for the person being supported. The additional funding provided in the 2002-03 Budget provided a welcome boost for existing and additional services. However, ensuring a sufficient and flexible supply of quality respite care is going to be an ongoing issue for carers and an ageing population. CA believes:

- respite care needs to be a primary service, not a secondary service of larger programs.
- carers require regular respite care that is responsive to key changes in their situation, with the capacity to also support them in emergencies
- most existing respite care is not appropriate for carers and those they support. More flexible models urgently needed by carers include: overnight and weekend support, cottage style accommodation and extended hours at day centres.
- the demand for services must be closely monitored to ensure that assistance is tailored to meet individual needs.

4.3c Counselling services

Counselling services for carers are a critical component of a comprehensive package of carer services. Carers are known to be at risk of poor physical and mental health including depression, dysfunctional family relationships and marriage and relationship breakdown.

The development of expertise in counselling for carers and their families is long overdue and should be alongside specialised services for grief counselling and sexual abuse. A range of carer counselling models, including personal counselling, relationship counselling, family conferencing and telegroup counselling is required. Along with respite services and in-home support services as an ongoing feature of community care, sufficient resources must be allocated to meet the demand for counselling as an integral component of support for carers and the ageing.

4.3d Education for carers

Accessible education support is an essential component of carer support services. Informal, practical instruction and advice tailored to the immediate and continuing needs of carers in their caring role and appropriate to their age and individual life stage is required.

Most carers currently do not have access to appropriate education programs to assist them in their caring role. In a recent national health and wellbeing survey¹⁹ 33 per cent of respondents report physical injuries as a result of providing care, but 49 per cent of respondents had never received information or practical training.

Flexible, carer focussed education activities in such areas as self care and coping with loss and grief must also be a key feature of carer support services to help them manage their circumstances, make appropriate decisions and maintain their wellbeing.

4.3.e Residential Care

When carers can no longer manage caring at home, the person they support should be able to access suitable residential care without difficulty. Many carers currently report inadequate staffing levels and lack of trained staff in residential facilities. As a result carers are called upon to assist with meal times and recreational activities. While many carers wish to continue to participate in residential care support, they do not wish to be acting as replacement staff.

Recommendation

CA expects in-home support services, respite care, counselling and education for carers, and quality residential care to be ongoing, long term features of community care and caring for the aged. To ensure carers receive the support they need for their care to be sustainable, these services need to be readily available, affordable, flexible in their delivery and of a high quality. Therefore these services must be monitored closely and resourced sufficiently to ensure that a quality service is delivered and demand is fully met.

¹⁹ Carers Australia, *National Survey of Carer Health and Wellbeing Survey*, 2000

4.4 Workforce flexibility

Changing demographics could potentially create new opportunities for older people in the workforce if fewer jobs are taken up by younger people and if people are able to delay retirement. Most carers who provide the main source of unpaid support are of workforce age (77 per cent of primary carers are aged 18 to 64 years) and many of them want to continue, resume or take up employment and education opportunities. However, these people have very limited choices due to inflexible workplace practices and inflexible financial support that discourages them from combining work and their caring responsibilities, and having limited access to suitable alternative care.

As the British study referred to in Section 3 indicated, carers and potential carers may be unwilling to give up paid work to take up caring responsibilities and prefer to seek a balance between work and caring responsibilities. For employers to retain quality employees and maintain the morale of employees with caring responsibilities, they must offer options such as flexi-time, staggered hours, time-off in lieu, compressed working hours, shift swapping, self rostering, annualised hours, job sharing, part time work, carers leave, and working from home.

Such workforce flexibility offers benefits to employers because they attract and retain quality staff; to employees because they have more control over their time and can balance the demands placed on them; and to those in need of care because the wellbeing of their carer is enhanced. This is subject to adequate alternative care being available for the people in need of care so that those carers wishing to continue to work or return to work can manage their situation.

Recommendation

That the Government work with other employers to develop, promote and implement carer friendly employment policies that are mutually beneficial to the employee and employer.

4.5 Retirement income

While the policy of successive governments has been to encourage people to financially provide for their own retirement, our current superannuation system is designed for people in long term continuous employment. This can be problematic for people who because of their caring responsibilities are not able to work, are forced to retire from work early, have disrupted employment, work part-time or casual or have low paying jobs. These situations mean carers have a reduced capacity to save for their retirement, particularly women in the middle age group who often have limited opportunity to work and accumulate superannuation. As a result they are more likely to be welfare dependent and on very low incomes in their own retirement and financially penalised for their caring responsibilities.

Caring often involves unexpected high expenses such as house or car modifications which require large amounts of capital. For many carers such capital is invested in superannuation which is preserved and inaccessible until retirement age, or taxed heavily where a component is able to be withdrawn. More flexibility is needed in these circumstances to assist carers with limited funds to meet their responsibilities and sustain their caring and wellbeing.

With current retirement income policies providing incentives for people to work longer through measures such as the Age Pension Bonus, carers are again disadvantaged. Carers are naturally feeling marginalised and anxious about their financial future and ability to provide for themselves.

Recommendation

That particular consideration be given to the circumstances and needs of carers in developing retirement incomes policy and superannuation regulation.

4.6 Income support and financial security

Income support and financial security is the most pressing area of need for many carers who struggle financially with everyday living expenses. Carers find it difficult to make ends meet with basic living costs, and even harder to cope with unavoidable and non-claimable costs associated with providing adequate care.

In 2001:

- 23,268 (18 per cent) people were caring for a person aged 65 and over who were receiving the Carer Payment²⁰. (This figure does not include aged carers receiving the Aged Pension.)
- 68 per cent of these recipients were women.
- a large proportion of persons receiving the Carer Payment and caring for a person aged 65 or over, were aged 45-64 (65 per cent of men and 72 per cent of women).
- 68,683 people caring for a person aged 65 and over who were receiving the Carer Allowance²¹.

In a phone-in conducted during Carers Week in 2001, 54 per cent of the calls to state and territory Carers Associations concerned financial issues. For these carers their financial hardship was a result of:

- limited access to social security payments
- inadequacy of social security payments

²⁰ *Australia's Welfare 2001*, AIHA, p. 211

²¹ The Carer Allowance is not means tested, whereas the Carer Payment is.

- giving up work to care; and
- incurring extra costs due to their caring role.

Extra costs incurred include such items as special care products, equipment, transport and communication which the current Carers Allowance of \$42.65 week is often insufficient to cover.

Again, for caring to be sustainable in the long term, income and financial security is paramount and will influence peoples' choices and decisions. As a long term issue in finding strategies to address the ageing population and the care of those in need, income support and consideration of the extra financial costs involved is critically important.

To address this critical issue, the current Carer Payment system needs to be restructured in consultation with carers, with an agreed time frame to phase in major changes as part of the Government's plans for welfare reform and to review the overall income support system.

Recommendation

That the Government work with Carers Australia to develop a more equitable and adequate system of income support that:

acknowledges and assesses more fairly both the different levels of care requirements of the person in need of support and assistance and the full context of the caring situation.

includes effective measures to offset the extra costs of care

addresses the needs of carers living in rural and remote areas

provides significant incentives and financial support for carers of workforce age to participate in education and employment and build their superannuation and retirement incomes.

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