

Submission on the Towards a National Carer Strategy Discussion Paper

The Benevolent Society

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1. Introduction

The Benevolent Society appreciates the opportunity to provide input into the development of the National Carer Strategy and, more specifically, to comment on the questions posed in the *Towards A National Carer Strategy Discussion Paper*.

1.1. About The Benevolent Society

The Benevolent Society is Australia's first charity. For almost 200 years we have been leaders in identifying the evolving needs of the community and in pioneering vital social reforms and services. The Benevolent Society's purpose is to create caring and inclusive communities and a just society. We believe that building stronger communities will lead to a more inclusive Australia.

Snapshot of The Benevolent Society

- We are a secular, not-for-profit organisation. We employ 800 staff, assisted by 700 volunteers, who in 2010 supported more than 31,000 people.
- Our largest areas of work are with children and families, ageing and community care, community development, mental health care and leadership programs. We operate from 55 locations primarily in New South Wales and in Queensland.
- Our revenue in 2010 was \$65 million. Approximately 85% is spent directly on our services. A further 8% is spent on our leadership programs, social initiatives and research.
- We receive financial support from federal, state and local governments, businesses, community partners, trusts and foundations. In 2010, 76% of our income came from government sources. Fundraising, trust and foundation grants provided another 4%, client fees generated 9% and our investment income contributed 6%.
- The Benevolent Society is a company limited by guarantee with an independent Board.

1.2. The Benevolent Society and carers

The Benevolent Society works with carers primarily in southern, eastern, northern and Nepean/Hawkesbury areas of Sydney. The Society provides direct assistance to carers through:

- the Carer Respite and Carelink Centre for southern and eastern Sydney which provides outreach, assessment, information, support, advocacy and links to services
- in-home, community-based and residential respite care on a planned and emergency basis
- carer education, support and training, carer support groups and activities
- consumer-directed carer programs.

We also work with and support carers of people who are clients of our other community care services and are receiving aged care packages, domestic assistance, food services, centre-based day care, case management/brokerage services or post acute care services.

The Society has experience in supporting carers of frail older people, people with dementia, children or adults with a disability, people with mental illness or terminal health conditions. We support carers of all ages, from teenagers looking after a family member, to ageing carers of adult children, to older couples caring for each other, and everyone in between.

Our carer services place a priority on reaching 'hidden' carers and make particular efforts to reach and support carers in indigenous communities, geographically isolated people, carers from culturally and linguistically diverse backgrounds and gay, lesbian, bisexual and transgender and intersex carers.

Our Carer Respite and Carelink Centre has well-established and effective processes for initial and ongoing assessment of carers and the people for whom they provide care. Assessment is strengths based (capturing carers' interests, resources, skills and goals), carer-directed, individualised and fluid in response to changes in their circumstances. These values are maintained throughout the Centre's relationship with individual carers and in each person's Care and Support Plan.

Care and Support Plans are developed in partnership with carers and encapsulate their short and longer-term goals, activities towards attainment of these goals and the services to be provided. Plans are written in the words of clients, are created and owned by them.

The provision of appropriate and timely respite care is only one aspect of care and support planning. Our practice aims to be holistic and to provide creative and flexible linkage for carers to other services, support networks, information, education and the community.

The Benevolent Society is further exploring way of working with carers that build carers' resilience and ability to continue as carers (if they wish to do so). We also work in partnership with other carer programs in the areas in which we operate to develop new responses to carers' needs.

2. Question 1: Do you think the Strategy as outlined in sets the right direction to meet the vision and aim to better support carers?

Vision:

Carers are recognised and supported at all stages of caring so they can maintain their health and wellbeing and take part in all aspects of life in Australia, including work, community and family life.

The Benevolent Society is broadly supportive of the intent of the proposed vision and aim of the Strategy. However we believe they should both be improved and strengthened.

Firstly, carers want and need more than just 'recognition'. They want understanding and appreciation of the complexity of their role, their varying situations and needs, and acknowledgment of their right to continue to participate in all aspects of community life.

Carers want acknowledgment of their skills and knowledge, often built over many years, of how to manage the health and other needs of the cared for person, and of what would make the most difference to their lives and to those of the cared for person. They want services that will give them support and guidance but not take over their lives, and they want understanding of how difficult it can be to hand over the care of someone you love to strangers.

The Strategy also needs to recognise of the role played and support needed by people who are primary carers – who do the 'heavy lifting' in caring for a person – at the same time as recognising and supporting the role played by a broader group of people (usually other family members and friends) who may also play a significant role in caring for a person.

There is, of course, no end to the permutations as to the different roles played by family members and friends in caring for a person and every situation will be unique in some respects. In some situations it may be counter-productive to identify one person only as the primary carer.

The challenge for governments and service providers is to both recognise and support individuals who play a primary caring role (whether on their own or shared with other people), whilst also recognising and supporting the wider network of people who play a role as carers. Governments and services providers also need to recognise that caring situations may be variable. For example, they may be episodic and planned as with an adult child with a disability who may come home for weekends, or episodic and unpredictable as in the case of carers of people with certain mental and physical illnesses, or be marked by rapid changes as is often the case when people are in palliative care.

The Strategy should make a strong statement about the value of the caring role and the work of carers and make mention of the positive aspects of caring. While it is absolutely critical that carers receive better understanding of and support in their often difficult, time-consuming and wearing roles, there is a danger of undervaluing the work of carers if we focus wholly on the negative aspects of caring. This does a disservice to the many carers for whom being a carer gives a lot of meaning, is a central part of their purpose in life (at least for a period) and from which they derive great satisfaction. Other positive aspects of caring may include the strengthening of relationships, acquiring of new skills and personal growth.

The Strategy should acknowledge that being a carer is an extension of other pre-existing aspects of people's lives as wife, husband, partner, son, daughter and so on, and that these relationships continue along with the caring role. Carers often have to manage multiple roles – as a carer and paid worker, as a carer and parent of dependent children, as carer and student, as a carer of several people, or as both carer and 'cared for' at the same time. Also, caring does not necessarily stop completely once the cared for person, for example, moves to residential care whether short term or long term.

The Strategy should have a clear statement as to whom the Strategy does and does not refer. The term 'carer' is used differently in different contexts. Even within our own organisation it can mean a carer of frail older person or person with a disability, mental illness or medical condition; or it can mean a carer of children in out-of-home care (foster carer), or a paid care worker in community or residential settings.

Aim

Policy, programs and services for carers are coordinated, responsive and targeted at all stages of caring.

We recommend that the Aim be reworded to more clearly reflect carers as playing the central driving role, with the onus on governments and services to listen to and respond to their needs, circumstances and aspirations with appropriate coordinated policies, programs and services. We suggest that the aim be reworded along these lines: *Policy, programs and services for carers are designed to respond to the needs, circumstances and aspirations of carers at all stages of caring.*

3. Question 2: Do you agree with the five goals outlined in the discussion paper? and Question 3: Tell us if you have any suggestions about how the goals could be improved.

Goal 1 – Better recognition for carers

With the provisos mentioned above about the term recognition, this is supported. It is understood that this is a high level goal, but much work will need to be done to translate it into action across government and public and private service providers, so that the results listed become a reality.

We recommend some rewording to encompass better recognition of the caring role, i.e. what carers do, as well as recognition of carers.

Consulting with carers requires a range of approaches beyond just consulting with peak organisations.

Goal 2 – Better support to help carers work

The financial penalty paid by carers through their lower workforce participation is well established and we therefore support the goal of better support to help carers work. However, the goal should be broadened to encompass the circumstances of carers for whom paid work is not possible or is unrealistic. We recommend that it be broadened (or an additional goal added) to refer to ensuring that:

- carers have access to adequate income support, as well as support to help them work or to undergo training and education
- carers are better supported during the transitions that will occur in the life of the person they are caring for, or their own life, including support to re-engage with the workforce when their caring role decreases or ends
- carers' future financial circumstances in retirement are not undermined.

As the Sex Discrimination Commissioner and Commissioner responsible for Age Discrimination has noted, the work of carers is not recognised or rewarded as work in the retirement income system. Instead, those who undertake unpaid work are presented with a financial penalty leaving them significantly more vulnerable to poverty in their own retirement. As she has indicated, approximately 25% of Australian women in their 50s are carers of other people.¹

Greater flexibility in the workplace and employer understanding of the demands on carers are still needed, such as through flexible hours, allowing reasonable time during business hours to liaise with health services and care services on behalf of the person they care for, and allowing reasonable use of phones and computers related to their caring role.

We know from our own experience as an employer of paid care workers – often women in their 40s and 50s – that flexible workplace arrangements that allow for ongoing or episodic caring responsibilities are a factor in attracting and retaining workers in an industry where workforce shortages are projected. The Benevolent Society would be supportive of extending the right to request flexible work arrangements to recognise all types of caring responsibilities, not just those of parents of children.

Income support policies, Centrelink procedures and employment programs should recognise that it is very difficult for someone who has been a full time carer of a child with a disability for 30 years, for example, to get into the workforce. Many carers receive income support other than a carer payment, for example, an age pension or Newstart, and these too should recognise the needs and circumstances of carers especially when these change.

Goal 3 – Better information and support for carers

This goal is supported. A range of strategies will be needed to achieve this goal. They should include national social marketing strategies as a technique to reach ‘hidden’ carers who are not reached by current methods of information provision. Hidden carers include people who do not see themselves as ‘carers’ or who do not even recognise the term. Some carers prefer to see themselves as a husband, wife, son or daughter, rather than as a carer, and see the term carer as a denial of their main role and responsibility as husband, wife etc. Carers of a spouse or partner are least likely of all carers to actively seek help.

There are many barriers to carers’ use of services and take up of entitlements. Information and support strategies cannot rely on carers asking for assistance if they are unaware that support exists or that it might be helpful to them.

Goal 4 – Better education and training for carers

This goal is also supported. However we are concerned at the possible implication that the transfer of training and skills about caring is all one way. While training for carers can certainly be helpful, carers also bring invaluable knowledge and skills to the caring situation and this too should be recognised and valued.

¹ Australian Human Rights Commission (2009), Accumulating poverty ? Women’s experience of inequality over the lifecycle: An issues paper examining the gender gap in retirement savings. September 2009.

Goal 5 – Better health and wellbeing for carers

This is supported.

The Strategy should acknowledge that carers experience the lowest levels of wellbeing of any section of the population. There is a need for a comprehensive range of strategies to improve carers' physical and psychological wellbeing.

This will also require shifts in the approach of carer support services from one of simply offering services such as respite, to focussing on supporting carers to build or re-build their own health and wellbeing.

4. Question 4: What should the Australian Government focus on under the goals to better support carers now and into the future?

See above.

Major reforms of health and aged care are underway under the COAG agreement and national health reforms. It is important that a consistent approach to the needs and circumstances of carers is maintained, once support for carers of people with disabilities and support for carers of older people become the responsibility of different levels of government.

Similarly, a focus on carers should be maintained in the re-design of the 'front end' of aged care currently underway.

In this submission we have highlighted the wide variability in the circumstance and needs of carers. Currently the range of support service available to carers is still quite limited and narrow. A broader range of service approaches is required to better respond to the needs and aspirations of carers in different circumstances and at different stages of their lives – including employed carers, carers with episodic support needs, carers of people in palliative care and young carers in transitional phases such as when entering the workforce and leaving home.

Finally, the implementation of the Strategy will require an appropriately skilled and trained paid workforce.

5. Question 5: Is there anything else that you would like to add that has not already been captured?

The Strategy makes little mention of young carers who are teenagers or young people. Young carers of a parent or sibling with a disability or illness rarely have any real choice about becoming a carer. It tends to become part of their life as a family member. They may have little or no experience of how life could be any other way. At the same time, they may experience genuine reward from their role and this should be celebrated and supported.

Greater understanding is required of the particular issues for young carers, such as the psychological and emotional issues they may face. Ensuring that they have opportunities to socialise with peers is very important.

It is especially unrealistic and unreasonable to put the onus on young carers to ask for help.

While there is some reference in the document to 'all stages of caring' this should be explained more fully. There should also be acknowledgment of and respect given to carers who decide that they 'have had enough' and cannot continue in caring for the person at home any longer even with assistance from formal support services. This will not necessarily mean that their role as a carer ceases entirely.