

20 January 2011

National Carer Strategy
Mail Drop Point 600
GPO 9848
Canberra ACT 2601

Attention: Esa Lahti

Dear Esa,

Re: National Carer's Strategy

National Seniors Australia (NSA) welcomes the Australian Government's commitment to leading the development of a National Carer Recognition Framework (Framework) to better recognise carers as part of its response to the report: *Who Cares ...? Report on the inquiry into better support for carers* by the House of Representatives Standing Committee on Family, Community, Housing and Youth.

We apologise for the lateness of this submission, but as the new Director of Policy for NSA my start date was on the day that submissions closed. We thank you for granting us an extension. This submission takes the form of a letter with the key points only given the timeframes that you have.

About National Seniors Australia

National Seniors Australia (NSA) is the largest organisation representing Australians aged 50 and over with some quarter of a million members nation-wide. This broad-based support enables NSA to provide a well informed and representative voice on issues of concern for people aged 50 and over.

The Process for the Strategy

NSA notes that the development of the Carer Strategy is important in responding to the challenges ahead. We provide a consumers perspective. NSA has consulted extensively with its members in the past on the issues around being a carer through a comprehensive grassroots process that enables members to contribute directly through communication with local branches, regional zone committees, State and Territory Policy Groups (SPGs), as well as the National Policy Office (NPO).

We seek to ask one preliminary question on the process of consultation for the National Carers Strategy. You indicate that you will be holding workshops for carer support organisations and service providers. In order to have input from those who care, some of whom may be involved with support organisations, we are hoping that arrangements have been made to enable people who want to be involved in workshops for access to respite so that they can be released from carer responsibilities when workshops are held, if they wish to attend. If this has not been considered we suggest you may wish to put some processes in place to enable their participation in the workshops.

Comments on the Five Goals Identified for the Strategy

NSA agrees with the 5 key goals identified (and notes that many of these were raised by the NSA in its preliminary submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth in July 2008). NSA is pleased to see the goals formulated as the basis for the strategy namely:

I. Better recognition for carers

NSA's recommendations for the improvement of recognition of carers should involve:

- a. Establishing an Office for Carers which would coordinate a whole of government approach to supporting carers and ensure a greater coordination of service provision.
- b. Ensuring a mechanism for carers and carer representative groups to be regularly consulted and engaged in reviews of carer policy.
- c. Providing greater funding for research into carer issues to ensure changes to carer policy are informed by evidence-based research.
- d. The implementation of a national information and awareness campaign to recognise the work of carers and assist them in accessing support services.
- e. The adoption of a consumer –centred approach when considering reform/ carer strategy options.
- f. Inclusion of human rights principles within the strategy.

In delivering services to carers training should be provided not just to carers but also to the service providers which will enable service providers to recognise pressures on carers. Currently, often service providers make assumptions about carers. Carers provide quality care for their care recipients, but often experience poor health and wellbeing as a result. In 2005, 44.5% of primary carers (219,400) reported that their sleep was interrupted due to the requirements of their caring role. Of these, around 46.4% (102,000) had frequent interruptions to their sleep.¹ Moreover 72.4% of Australia's primary carers experience some form of detrimental effect from providing care. The most common is feeling weary or lacking energy (33.7% of primary carers); 29.2% often feel worried or depressed and 28.9% feel their well-being has been affected. Clinical studies have also shown increased rates of depression among caregivers.²

Not only do significant numbers of primary carers experience fatigue, emotional and mental stress, caring can also cause physical injury, especially musculoskeletal injuries from incorrect lifting, lowering and carrying or moving the recipient of care.³ A 1999 survey by Carers Australia found that 33% of carers reported having been physically injured at least once in the course of providing care, of which over a half were due to lifting or carrying.⁴ Service providers therefore need to respect the difficulties that carers face on a day to day basis but also to treat them with respect and understanding of the difficult contexts and settings they are in. Feedback has been that services can be difficult to navigate and access and often, when under significant other pressures, carers can just give up trying. International research has revealed that if referred more than three times most people just give up.⁵ This is a concept known as 'referral fatigue'. This is a reason why service providers need to be properly trained with a consumer focus in the delivery of their services. We also think that the strategy should operate within a human rights context. This is consistent with moves in the Federal Attorney General's Department which includes the development of a Human Rights Plan of Action.

Vulnerable and often disadvantaged groups, such as carers, are often reliant on government agencies for support and subsistence and can be more susceptible to infringements of their rights. NSA

¹ Access Economics (2005)

² Ibid

³ Ibid

⁴ Ibid

⁵ P Pleasence, A Buck, N J Balmer, R O'Grady, H Genn and M Smith, 'An Integrated Approach to Social Justice', *Causes of Action: Civil Law and Social Justice*, Legal Services Commission (2004a)

suggests obviating such infringements by integrating a human rights approach or principles to guide how systems/service providers respond to carers in the Carer Strategy would help. Recent case studies show that people both carers and service providers (when sufficiently armed with correct information about their rights, remedies and where they can go to seek help in a non-alienating environment and with support) have been able to generate change using the standards within the human rights frameworks to argue for improved conditions and treatment.⁶ This highlights that ensuring human rights compliance does not have to be litigation led and that resolutions can be negotiated by people without resort to the courts, using the language and culture of human rights. One recent Victorian case involved grandparents who were able to use human rights arguments with a local service provider to enable their grandson who had a brain acquired injury to access services in a more timely manner than service providers were initially prepared to provide. In another case, carers, whose child had learning disabilities, had been told the child had to travel to her special school by two buses. After raising human rights arguments through their advocate they were given easier access.

2. Better support to help carers work

- a. The strategy facilitates a framework that ensures respite services are appropriate, affordable, accessible and flexible to better meet the needs of carers.
- b. The framework consider steps that could ensure the lead in establishing care facilities for frail aged parents in Australian Government workplaces, similar to those provided for employees with young children. This could be phased in but with an aging population and in future a likely shortage of skills this would make it easier to retain older people in the workforce.
- c. Provide incentives for employers to ensure flexible workplace practices are available to carers.

Carers can become isolated and unable to participate in employment and in the community due to respite care services not meeting their needs. The strategy should incorporate processes to facilitate the designing service delivery options to take account of factors which include:

- high costs of respite care;
- lack of flexibility in the hours of operation of respite care services (particularly evenings, overnight and weekends);
- the availability of respite services, particularly in regional, rural and remote areas;
- the availability of appropriate respite care services for people with particular needs (i.e. children with disabilities or older adults with dementia); and
- the availability of respite care services which are culturally appropriate and sensitive.

3. Better information and support for carers

- a. Provide greater funding for carers referred to counselling services by the Commonwealth Carer Respite Centres to better address unmet need.
- b. Greater numbers of case managers and realistic allocated case loads for case managers to assist carers to plan for the future needs of their care recipients.

⁶ The British Institute of Human Rights, *The Human Rights Act – Changing Lives* (2006); L Clements, 'Winners and Losers' (March 2005) 32(1) *Journal of Law and Society* 36; P Fennell, 'Convention Compliance, Public Safety and the (March 2005) 32(1) *Journal of Law and Society* 10; A Lawson, 'The Human Rights Act 1998 and Disabled People: A Right to be Human?' in C Harvey (ed) *Human Rights Law in Perspective: Human Rights in the Community (vol 15 Human Rights: Agents for Change)*, British Institute of Human Rights, Hart Publishing (2005), 135 and T Harding, 'Older People' in C Harvey (ed) *Human Rights Law in Perspective: Human Rights in the Community (vol 15 Human Rights: Agents for Change)*, British Institute of Human Rights, Hart Publishing (2005), 113.

4. Better education and training for carers.

Access for carers to education and training means access to respite support, to enable carers to be better able to participate.

For carers, access to education and training is more difficult than for most people as they have limited capacity and freedom due to their carer responsibilities. The mere offer of educational and training opportunities for carers will not necessarily mean they can avail themselves of them. Even capacity to utilise online opportunities can be heavily impacted upon depending on how severe and attention requiring the demands of the person being cared for may be.

Some issues confronting carers include social isolation, frustration, coping strategies for dealing with complex and multiple needs. Information about where to find help, telephone services and parenting and health resources are critical. These include information about respite care, health and well being, financial concerns, community resources and support, grandparent and relative support groups, education, grief and abandonment, fear, anxiety, insecurity, mental health, safety, people with special needs, challenging behaviours, aged care services, positive strategies, early intervention services, child and disability health service, legal advice and access to counselling and social welfare services. These may be for either the carer or their dependant.

5. Better health and well being for carers.

- a. Provide free regular health checks for carers through GPs to assess carers' physical, mental and emotional health and wellbeing.
- b. Ensure that carers are included and recognised as part of the health care team.
- c. Facilitate a national carer health and wellbeing awareness campaign.
- d. Ensure respite services are appropriate, affordable, accessible and flexible to better meet the needs of carers. Again, pressures of constant care can lead to a decline in the health of the carer through tiredness, physical and mental strain.

Conclusion

We suggest a further goal (Goal 6). Any Carer Strategy needs to not only think short and medium term but have a capacity to anticipate and prepare for longer term. One of the challenges is, as carers' age, they become frailer and less capable of physical exertion. In many cases, they lose a partner and worry about who and how their dependant will be cared for into the future.

Given carers provide a critical and essential service in protecting vulnerable citizens relieving the State of many onerous caring responsibilities; it is paramount that the Carer Strategy works through how, as a society, we are going to deal with this as the population ages and lives longer? Key in preparing for this will be input and ongoing reflection and actions to prepare and put in place good ideas. To enable this feedback and policy input from consumers is going to be essential. We therefore suggest a further goal, 'Enable and facilitate better participation of carers in society and decision making'. Although listed as a subset in many of the goals already, having it as a Goal in itself will give prominence to it and enhance the ability to ensure the strategy is delivered from a consumer perspective.

We wish you well in your efforts to develop the strategy and should you have any queries please do not hesitate to contact me on (02) 6230 4588.

Yours Sincerely,

Dr Liz Curran

Director of Policy