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Submission No. 695

(Inq into better support for carers)

Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth
PO Box 6021
Parliament House
CANBERRA ACT 2600

Dear Secretary,

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers in my capacity as National Coordinator of the Defence Special Needs Support Group and as a mother and carer for my 16 year old son who has severe multiple disabilities.

Our organisation, established 15 years ago, provides support, information and assistance to those Defence Force families who provide care to people with a disability or special needs. We are a national charity run by volunteers, all of whom are either a carer or a person with a special need or both. The Defence Special Needs Support Group is also recognised by Defence as the peak body for families and dependants with special needs.

The Defence Special Needs Support Group has been very proactive since its inception in introducing or recommending policy at many levels of Government with the aim to assist families moving intra or interstate not just those in Defence. These policies related to:

- Portability of equipment on loan through State/Territory equipment schemes;
- Priority of access for therapy services – not based on time spent on waiting lists;
- Standardized assessments for early intervention and education;
- Portability of Post-school options/disability funding
- National incontinence scheme to include those under 16
- Portability of Federal Disability funding for students and alignment between State/Territories re disability funding in education
- Portability of the Special Needs Subsidy Scheme for childcare
- Continuation of Carers Allowance whilst the Defence family is relocated overseas
- "Support to families with special needs" – Defence policy to assist families/carers both within Australia and overseas

Whilst we currently have a family membership of approximately 3000, according to the 2003 Defence Census there are 4201 members with dependants (ie couples/families) providing care to someone with a disability or special need. This equates to 11% of Defence Force families. Data from the 2007 Defence Census is not currently available but based on the increase in Defence numbers, it can be estimated that there is approximately 5000 families that are now providing care.

In real terms, in many of these families, the primary carer is caring for more than one person with a special need. Defence carers not only encounter the same problems in their caring role as their civilian counterparts (isolation, health issues, lack of employment options, financial difficulties and problems with access to support and services), their caring role is compounded by relocating on average every two or three years and at times being a sole carer whilst their partner is on a lengthy deployment. In addition, Defence carers do not have the luxury of an extended family or social network to fall back on for support, particularly if they are newly arrived in location. These additional burdens greatly add to their physical and psychological wellbeing. Our carers are quite diverse, living in remote, rural, region and metropolitan areas and they include ABTSI, older carers, young carers, new carers, sole carers, CALD and male and female carers.

However, Defence is not the only mobile workforce in Australia and indeed according to the ABS August 2006 Census between 2001 and June 2006 an estimated 1.87 million people moved to another state or territory. ABS Australian Demographic Statistics, Mar 2007 estimates of quarterly interstate migration showed there were 344,900 persons moving interstate within Australia for the year ended 31 March 2007. This doesn't include those persons moving intrastate.

As Australia's mobile population continues grow, there is a real concern that carers who need to relocate due to work, family or other reasons will continue to be disadvantaged if appropriate services and supports are not put in place and the issue of mobility not addressed at all levels of Government.

In addressing the Terms of Reference, the information provided has been taken from Defence carers across Australia.

1. The role and contribution of carers in society and how should be recognised

All in cases, carers felt that they were not valued nor recognised for the contribution that they make in society. Some expressed concern that there was no National Carers Strategy or Policy at a Federal level to recognise their caring role. They felt that this would assist with job security, support and appropriate service provision and provide recognition at a high level.

2. The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment.

The barriers that our carers have encountered particularly in relation to employment are:

1. Lack of childcare places, long waiting lists and/or lack of appropriate support for a child with a disability
2. No before or after school care for a child with a disability over the age of 12
3. No appropriate support or no places available for a young adult with a disability due to lack of funding or no funding when moving into a new area (also same for when caring for an elderly dependant)

4. Cost of putting in appropriate services privately often outstrips the income received
5. Lack of flexible work options
6. Employers seemingly not interested in employing someone who has also a caring role

Barriers to social participation in every case are lack of appropriate, **flexible and on-going** respite options. One carer said that whilst her teenage son can go to the "Saturday morning club" she would actually like respite a few hours each week or even every second week so that she could go out to a movie or go to a craft group.

Respite options vary from area to area and there is inconsistency between HACC eligibility criteria. A carer may receive a small allocation for in-home respite in one region but when they relocate there is no HACC funding and the comments made by the agency are that they only fund elderly clients not those caring for children.

Carers would like to see flexible on-going respite. Respite where it can be used either in-home or out-of-home (ie take the care recipient to a recreation activity) and not necessarily the same day, same time each week.

Respite waiting lists in many areas are closed or are extremely long with agencies reporting that they not taking any more referrals. For example in Townsville, the majority of respite is geared towards those caring for the elderly so if you relocate to Townsville and you care for a severely disabled member of your family, is it highly unlikely that you will receive any respite support for quite some time (other than short term or emergency offered by the CCRC). Similar situations occur in Canberra, areas of Melbourne, Sydney and Brisbane.

3. The practical measures required to better support carers, including key priorities for action

1. Increase Carer Allowance and loosen the eligibility criteria for the Carer Payment
2. Increase Continence Scheme – most of our carers report that they are spending between \$3000 - \$6000 per year on continence products and yet they only receive \$475 through this scheme.
3. More flexible on-going respite
4. Increase funding and reduce waiting list time for equipment
5. Introduce a National Equipment Strategy so that it is equitable across Australia in terms of what is supplied and access
6. Introduce a Tax Rebate to offset the costs related to age and disability care to support working carers
7. Appropriate coordination and linkage between disability services through all levels of government
8. Ease of movement and continuation of services and supports between States/Territories
9. Immediate assistance and information upon becoming a "carer"
10. Appropriately funded and increased access to services and supports ie speech therapy, occupational therapy, overnight respite accommodation, aged care facilities, Young people with ABI
11. Coordination of services where the carer is required to access other service systems whilst receiving disability support ie mental health/aged care
12. More disability packages for use in the provision of purchasing appropriate services and supports

4. Strategies to assist carers to access opportunities and choices, including strategies to increase the capacity for carers to make choices within their caring role, transition into and out of caring and effectively plan for the future

The majority of carers interviewed could not comprehend planning for the future, particularly as they didn't know where they would end up living once they left Defence. As one carer commented "I just get through each day as it comes. I get up in the morning, care for my daughter, sleep when I can and then it starts all over again".

I would be happy to provide further follow up at any stage.

Yours faithfully

Margaret Fisk OAM
National Coordinator
Defence Special Needs Support Group