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...from an original idea in 1878

4th July 2008

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

The Julia Farr Association (JFA) wishes to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

JFA and its predecessor organisations have been involved with the disability community for 130 years. The organisation holds that the following values should inform policy development in this area:

- Personal authority – where people living with disability and their families have and exercise control over the key decisions in their lives
- Social inclusion – where people living with disability and their families are included as active citizens in the life of the wider community
- Capacity building – where people living with disability and their families, through access to experiences and support, are growing their capacity to enjoy active lives of choice. This also includes the wider community growing its capacity to be inclusive and supportive of people living with disability and their families

JFA is not a service provider, nor an advocacy agency, has no political affiliations, and is not Government-funded. As such, we feel we are in a good position to offer comment and analysis without vested interest.

JFA, through enquiry and networking in the disability community and the wider community, seeks to foster innovation, share useful information, and identify and promote policy and practice that may be helpful in improving the life chances for people living with disability and their families.

We applaud the initiation of this inquiry into better support for caregivers and have based our comments on our qualitative research with people across the South Australia disability community.

This includes feedback from over 200 people at our annual *Loop* conference and input from the Tell Us survey, where over 800 people, including many people in caregiving roles, provided information about their experiences living with disability issues.

People living with a disability speak of their daily struggles. From their comments we make the following representations:

- Often, caregivers are time-poor for anything other than the responsibilities involved with giving support. One of the reasons given why many caregivers don't speak up on issues is because they are too tired¹;
- Within a life as a caregiver, people want choices and access to the same opportunities that everyone else would reasonably expect to live a satisfying and full life, such as work, income, relationships, leisure pursuits, holidays¹;
- In line with the recognition given to other endeavours that contribute to our society, caregivers want acknowledgement of their role's contribution, not just in terms of the welfare of the care recipient, but also in terms of the financial savings to society. For those who wish to undertake care-giving, these benefits need to be acknowledged and supported in ways that enable the caregiving role to be sustainable²;
- Caregivers often do not have access to the workforce due to barriers of lack of available time and an inability to find employment flexible enough to fit with the support needs of the person they provide support to³;
- People who want to give time as caregivers often cannot afford to do so, because financial commitments prevent them from choosing this role as a financially viable option in life (T Applebee 2008, carer, pers. comm., 26 June);
- Caregivers often are unable to plan as the notion of 'the future' for them revolves around the person they care for (T Applebee 2008, carer, pers. comm., 26 June).

The Julia Farr Association provides the following solutions for better support for Australia's caregivers.

¹ Julia Farr Association 2008, 'The Loop 2007 conference proceedings', Proceeding Notes, Julia Farr Association, Unley, SA, 30 June.

² Dalton, C 2008, *The future of Australian Governance. People with disability and family carers*, viewed 30 June 2008, <http://www.juliafarr.org.au/cms/doc_viewer.asp?RID=449>.

³ Edwards, B, Higgins, DJ, Gray, M, Zmijewski, N & Kingston, M 2008, *The nature and impact of caring for family members with a disability in Australia*, Research report no.16, Australian Institute of Family Studies, Melbourne, Victoria

- A detailed review of the actual cost of living with disability, both for the person and their main caregiver(s). This would capture the financial costs (including opportunity costs) in addition to the social and emotional costs associated with lack of access and opportunity to many areas of life valued by the majority of Australians. This review would inform the reconstruction of a reasonable and useful formal system of Commonwealth support for caregivers. The information could also be forwarded to the ATO as it considers evolving tax system arrangements. In this way, the ATO would have the opportunity to evolve a tax system that helps, not hinders, people living with disability and their families.
- Introduce Individualised Funding (also known as self-managed funding) packages for people living with disability and their families. With greater control over the decisions about the support they receive, the role of people providing unpaid support can be legitimized and recognised as a valuable contribution to the life of the person living with disability. Such packages provide flexibility to help address issues for caregivers as well as for the person living with disability. For more information about Individualised Funding please go to www.juliefarr.org.au
- Work with the states and territories to establish better individual planning arrangements. These should have the following characteristics:
 - The plan should be anticipative and proactive so that people don't have to wait until their lives are in crisis before something happens;
 - The plan should take a broader view of the person's life, beyond personal care, equipment and therapy, and into areas such as employment, relationships, voice, belonging and so on.
- Incorporate the above three points into a new and innovative system that can assess the individual needs of each caring situation and allocate adequate resources that provide flexible options for people so that entering a caregiver role for a loved one becomes a positive lifestyle choice rather than a last resort due to lack of alternative options.

Thank you for taking JFA's views into consideration as part of the Committee's Inquiry.

Yours sincerely



Robbi Williams
Chief Executive Officer
Julia Farr Association