

Submission for the Inquiry into Better Support for Carers

Ellen

I respectfully offer the following comments to the inquiry. My caring responsibilities have perhaps restricted the quality of the submission and yet I trust it will raise and/or endorse issues that are of relevance to the government—I know they are important to me as in individual with caring roles for close family members with disabilities as a result of acquired brain injury through accident and stroke; mental illness; and with concern for the caring roles of close friends with children with intellectual and physical disabilities. I have had 'hands on' caring roles for some 14 years. I knew I wanted, and still want to, care not only about, but for the people involved with the aim of a contented quality of life for us all. However, I found the 'how to' of caring much more challenging than the desire to undertake the role.

1. The role and contribution of carers in society and how this should be recognized
 - a. Acknowledgement that we are people who have taken on a caring role, not carers who are trying to fit in being people in our lives
 - b. Legislation such as the Carers Recognition Act 2004 (Western Australia)
 - c. Economic recognition
 - d. Acknowledgement that carers are essential partners in a caring relationship. For example in student/teacher or patient/health professional relationships, expectations are put in terms of 'good' outcomes for the student and patient. However, in order to achieve this, training, supports, infrastructure and rewards (financial and social) are provided to the teacher and health professional. Why not for carers?
 - e. Recognition for the different forms and levels of caring
 - f. I am aware that carers who identify their caring role are more likely to have better wellbeing because they access appropriate services. Service providers, health professionals, others who have the potential to impact on the caring role and the systems involved, need to have a recognition of the caring role and effectively have a safety net in place to ensure that carers are involved in service delivery, assessment, planning and review without those people needing to self-identify as carers.
2. The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment
 - a. the acknowledgement that there is a continuum of levels of care from perhaps a few hours a week to almost all of the hours available in a week

- b. bringing awareness to employers as to the benefits of employing carers—eg the work of Employers for Carers done in the UK headed by Caroline Waters of British Telecom
 - c. looking at the possible myths that carers might be unreliable, untrained etc
 - d. helping carers to overcome guilt that they should not be able to enjoy themselves—perhaps by looking at what community expectations really are—for example research done by Nancy Guberman in Canada
 - e. I think the ‘It’s about time’ report of HREOC was very useful
 - f. identifying suitably valued positions that may best suit different forms of the caring role
 - g. I like to refer to respite as taking a break from the caring role, not necessarily from the person being provided with care
 - h. Provision of respite that allows the carer/family to choose who will be involved in episodes of respite
3. the practical measures required to better support carers, including key priorities for action
- a. recognition as full citizens of our society
 - b. legislation to provide the initial incentive to acknowledge the role of carers and the potential benefits brought to caring outcomes through that recognition
 - c. respite that reflects the needs of carers—that is truly flexible, adaptable and responsive
 - d. respite that differentiates between the levels of caring roles (more, less) so that carers with higher inputs to the caring role are able to access more respite
 - e. that respite can be planned and still funded by the government
 - f. respite, both direct and indirect, that acknowledges different capacities carers have (e.g. carer denied CACP because they could resource most support themselves such as shopping, cleaning etc, but could not support the need for substantial ongoing respite to the number of hours afforded by a CACP)
 - g. carers often advocate very well for the person they care for, not so well for themselves—therefore, raising awareness of this and training to improve self advocacy
 - h. Lack of suitable equipment for people with disabilities, impacts on carers through physical means—extra lifting, pushing inappropriate wheelchairs, extra provision of care because of the potential of pressure sores, social isolation because mobility equipment is inadequate. These impacts also have the potential for follow on psychological impacts—life can become very tedious and the caring role can overtake the emotional needs that the person with that role has with significant others such as children, husbands, wives, partners, mums, dads, friends, etc
 - i. Finances—how do you support a family on a carers pension and allowance in today’s world of high costs—petrol, rent, and food. Perhaps politicians could give it a try. Remembering the income support again takes little

regard of the level of inputs to the caring role or to the stage of life that the people involved in the caring relationship are at.

- j. Decrease the amount of time carers must provide care in order to remain eligible for pensions/allowances—currently carers can ‘take off’ 63 days a year from their caring role - this does not even reflect usual working arrangements of a 37.5 hour week—indeed, carers do not even get the equivalent of weekends off in a year (104 days) let alone sick leave, holiday leave, personal leave..
 - k. Provision of dental support to residential care facilities—it can be difficult to transport people to the dentist—mobile dental clinics.
4. Strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future
- a. legislation
 - b. economic recompense/reward
 - c. respite that is appropriate in the length, access, costs, and models of delivery, to the emotional and physical capacities of carers, whilst taking account of the needs and best interests of the person receiving care.
 - d. adequate and appropriate equipment and assistive technologies
 - e. accommodation for people with care needs to meet the demand
 - f. education and training in the caring role for all who request/require it
 - g. respite plans and periods of ‘respite’ in respite accommodation included as ‘mandatory’ in discharge planning where the predominance of care will be provided by a carer
 - h. ACAT assessments that allow frailty as an eligible criteria so carers can access respite (I understand changes since March 2008 have affected ACATs assessments)
 - i. Providing opportunities for carer input as part of a discharge from respite plan—carers given time and space are more likely to be able to reflect on their needs and the requirements/resources to provide good caring outcomes
 - j. Funding that is sufficient to provide alternative accommodation with appropriate support particularly for people with disabilities—physical, intellectual or psychiatric - when carers choose to withdraw from ‘intense’ caring roles
 - k. That some form of training in the caring role becomes part of the eligibility to receive carers pensions/allowances
 - l. Workforce shortages impact on carers. Carers have to pick up the shortfall if a worker does not turn up; workers are not always well trained; workers still need orientation to the particular caring situation and carers often have to provide this which ‘eats’ into ‘respite’ time and the worry and concern that there is a mismatch of careworker to the requirements of the person with care needs, impacts psychologically on the carer. We need a

- workforce that, like carers, needs to be well resourced, valued, and appropriately rewarded for their contribution to the caring relationship
- m. Physical training such as that which could be provided by physiotherapists and occupational therapists to ensure carers can manage the physical aspects of their role and are provided with appropriate assistive devices
 - n. Forms of emotional, psychological type counseling to minimize the effects of the caring role—studies show how this impacts on the role and can remain after transition from the role.
 - o. Providing government funding to support people to remain in the community at least equivalent to the cost of the provision of appropriate supported accommodation.
 - p. In line with the above, the accommodation provided must be at least of such quality as to permit a standard of wellbeing accepted as appropriate by our society.
 - q. Carers who are eligible for the carers pension should also be automatically granted a carers allowance—I was speaking with a carer who thought she was only eligible for the pension and so has missed out on not only the allowance but the bonus associated with that allowance in recent years.
 - r. In the field of disability, carers can be faced with untenable work loads as their children with disabilities leave school and are unable to access funding to provide alternatives to education
 - s. Investigation into allowing families to provide paid support to a person with a disability (for instance a sister, uncle etc)—this would help overcome the workforce shortage and possibly help with finances within a household where there are these caring relationships.
 - t. Education and awareness raising of our population of the caring role—we all need to take an interest—research suggests that 1 in 2 people are likely to have a caring role at some point in their lives—this is direct impact for a lot of us; it also suggests that we may be the people with care needs—the other 1 in 2 side of the coin perhaps—and as such, I know that I would want my carer to be well supported and resourced and I would like to have an understanding of the implications of their role and how we could all work best together for beneficial mutual wellbeing.
 - u. Children with disabilities who become wards of the state are likely to have access to medical, therapy, etc supports and their foster parents/carers are often paid considerable sums to provide their care—what is the difference in the care provided (above and beyond that of being a ‘normal’ parent) that this is socially, morally acceptable—why can’t birth parents be paid these amounts...
 - v. To promote partnerships, philanthropical involvement and the like with corporate Australia—as relevant but particularly in the support of ‘non-core’ services such as helping carers link with each other for peer support
 - w. That in all we do, we assess what we currently have that is working and do not ‘throw the baby out with the bathwater’.

Thank you for this opportunity.