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Submission No. 886
(Inq into better support for carers)



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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. I make this submission on behalf of a core group of researchers at The University of Queensland who support the establishment of a Carer Research Centre:

- **Associate Professor Kenneth Pakenham**, School of Psychology, The University of Queensland
- **Professor Cindy Gallois**, Acting Executive Dean, Faculty of Social & Behavioural Sciences, The University of Queensland
- **Professor Desley Hegney**, Research & Practice Development Centre, School of Nursing & Midwifery, The University of Queensland & Blue Care
- **Professor Robyn Gillies**, School of Education, Acting Director of Research, Faculty of Social & Behavioural Sciences, The University of Queensland

Thank you for taking our views into consideration as part of the Committee's Inquiry. We look forward to reviewing any recommendations you make to improve life for Carers in Australia.

Submission: **Development of a Carer Research Centre**

This submission calls for the development of a Carer Research Centre that will integrate and focus research expertise in caregiving and link it with government and community priorities, to form a centre of research excellence with national and international standing.

Such a Carer Research Centre should aim to enhance the role of informal caregivers by the development of evidence-based interventions and policy which aim to optimise the physical, mental and spiritual health of this section of the health care workforce.

Centre Activities: The focus of a Carer Research Centre's activities should be guided by emerging impelling directions identified by the Centre, the health priorities of governments and national research funding bodies and by carers themselves who should be consulted through focus groups and consultation with carer groups. However, at a broad level the activities of a Carer Research Centre should be focused on 5 areas:

1. Support: Develop, evaluate and disseminate evidence-based carer support interventions and document the translation of this intervention research into public health practice.

2. Training: Develop, deliver and evaluate accessible carer training programs.

3. Services: Evaluate carer services (e.g., respite care) and provide an evidence-base to inform further optimisation and development of services; and develop and disseminate carer assessment protocols.

4. Health Professional Training: Train health care professionals to enhance their ability to work as a team with informal carers; and train and accredit staff in conducting carer interventions in service settings and provide some quality control of carer supports

5. Public Policy & Organisation Strategy: Provide an evidence-base for policy development through systematic policy-focused research, policy and economic analysis and research into the organisational arrangements for supporting carers.

A Carer Research Centre should function as a clearing house for research related to these 5 areas. This would include the dissemination of information to researchers, practitioners and policy and service planners.

A Carer Research Centre should collaborate with international and national research groups, remain informed of research developments elsewhere, and disseminate research findings from Centre projects. This process would ensure that the Centre continued to evolve, respond to data about the impact of interventions and other research outcomes and incorporates new knowledge about how to best assist carers within the health care workforce.

Centre Location: It is proposed that a Carer Research Centre be located within The University of Queensland for several reasons including:

- it has a track record of high quality research in the carer field
- a large number of researchers from The University of Queensland have voiced their support for such a Centre.
- The University of Queensland has a culture of carer research and expertise that would provide considerable infrastructure support that would scaffold the development of the Centre.
- Many researchers at The University of Queensland have established links with key government and non-government bodies, professionals and local and international researchers in the carer field.

Given that carer issues are pertinent to many disciplines, collaborative links should be cultivated with relevant carer researchers in other universities and research

centres. In this regard, it is envisaged that Carer Research Centre satellite nodes would be established in collaboration with carer researchers at other Australian universities. A Carer Research Centre should also develop and retain close ties with relevant carer consumer groups, community organisations and government departments.

Support for Carer Research Centre: While this submission has the personal support of a core group of researchers, over 40 researchers at The University of Queensland have expressed their support for establishing a Carer Research Centre. These researchers come from a range of disciplines (e.g., nursing, medicine, psychology, occupational therapy, physiotherapy, speech therapy, communication, education, sociology and economics) and from diverse university faculties (e.g., Social & Behavioural Sciences, Health Sciences and Business). Furthermore, the call for a Carer Research Centre has strong support from the peak carer organizations in Australia (e.g., Carers Australia, CEO Ms Joan Hughes; Carers Qld, CEO Mr Graham Schlecht), and many carers, health professionals and researchers. We also have a developing relationship with and support from the service delivery sectors. Over time the numerous carer research reports and submissions made to governments at national and state levels have included recommendations for the coordination, funding and support of carer research.

Background Information

In recent years informal caregiving has emerged as a public health priority of national concern. The 2.6 million Australian informal carers fulfil important roles in the care of people with illness and/or disabilities living in the community and, while previously not formally recognised as such, they are an essential component of the health care workforce. Informal care activities are often hidden and are part of the private domain of the family; however, unpaid caregiving is labour; it is care work. In Australia the replacement value of the care provided by informal carers with the purchase of formal services to deliver care in the home has been calculated at \$30.5bn per annum (equivalent to 3.5% of the forecast GDP and 62.2% of other formal health care) (Access Economics, 2005). The role of carers in the health care workforce has assumed greater priority recently because of shorter hospital stays and the limited availability of long-term care placements. Carers are involved to varying degrees in almost all aspects of care and provide a wide range of assistance and, therefore, substantially influence the quality of life experienced by persons with illness/disability. Hence, the contribution of carers to the health care workforce is critical to the sustainability of the current Australian health and community care systems.

There is a steady increase in the numbers of people providing care for relatives and friends with illness and/or disability. This is a consequence of the ageing of the population, an increase in the prevalence of people living with chronic illness and/or disability, and society's preference and government policies which encourage older persons and people with chronic illness and/or disabilities to remain in the community. Overall, the number of people requiring informal care is increasing at a much greater rate than the number of informal carers available. For example, a study by the National Centre for Social and Economic Modelling concluded that over the next 30 years the number of older people with a severe or profound disability is

projected to grow by 160%, whereas the number of carers will increase at a much slower rate (57%).

The varying and complex emotional, physical and practical demands of caregiving mean that caring for a person with an illness and/or disability involves a complex array of skills and is potentially very stressful. Recent large-scale Australian research showed that carers have the lowest collective wellbeing compared to all other disadvantaged groups examined ("The Wellbeing of Australians: Carer Health and Wellbeing", Carers Australia, 2007). This research also found that carers had an average depression rating classified as moderate depression. In general, Australian and international evidence indicates that family carers have poorer health and wellbeing than non carers. The maintenance of carers' health is a significant public health issue, as it determines their capacity to provide care for people in their homes who otherwise may have to rely upon publicly funded institutional health care. Hence, it is important that carers, as members of the health care workforce, receive the appropriate training and support in performing their caregiving roles.

Given the increasing number of carers in Australia, the key role carers play in the national health care workforce and the stress associated with their care work, it is essential that they be supported so as to ensure their optimal performance as unpaid health care workers. In this regard, evidence based, well coordinated, responsive and proactive carer training programs and support services must be developed. For this to occur research is required that identifies the training and support needs of carers. However, there is no facility in Australia dedicated to carer research. Much of the carer research throughout the nation is ad-hoc, fragmented, illness or disability specific and driven by particular interest groups. While there have been some important carer research conducted in Australia, much of this has been limited to "one-off" projects without follow up of the application of findings over the longer term.

Yours sincerely

Kenneth Ian Pakenham PhD