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Submission to House Standing Committee on Family, Community, Housing and Youth

July 2008

A.OC 10/7/08 Submission No. 657 (Ing into better support for carers)

Re: Inquiry into Better Support for Carers

The Social Policy Research Centre (SPRC) is a research centre at the University of New South Wales. The Centre exists to conduct research and foster discussion on all aspects of social policy in Australia. The Centre's research is funded by governments at both Commonwealth and State levels, by academic grant bodies like the Australian Research Council (ARC) and by non-governmental agencies. The SPRC currently employs over 40 staff conducting 60 projects within the area of social policy.

The SPRC has made major contributions to the development of social policy in Australia and internationally. The Centre regularly holds seminars and conferences and has an active publishing program. The Centre also fosters discussion of social policy research and policy issues by organising and hosting conferences, seminars and workshops, and supports the training and development of qualified researchers and teachers in social policy through in-house and external training initiatives and a program of higher degree research.

In the field of research on Carers, we have an active research program that concentrates on the experiences and needs of carers across the lifespan, including young carers, mid-aged carers and older carers. The program is concerned with looking at the contribution carers make to the wellbeing of the people for whom they care, and also looking at the costs to carers themselves. This research addresses the impact on carers, including access to income, education, training, employment, participation in social, sporting and other recreational activities with friends and community organisations. The impact on carers' physical and mental health is also examined. A core aspect of our body of research involves identifying the policies, programs and services at all levels of government, schools, post-secondary education, workplaces, and community-based services which support and assist carers and the people for whom they care.

Researchers at the SPRC are currently involved in several major research projects relating to carers. These are:

1. Young Carers: Social policy impacts of the caring responsibilities of children and young adults, an ARC Linkage grant project funded by the Australian Research Council.

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- 2. Grandparents as primary carers of their grandchildren: A National, State, Territory analysis of grandparent-headed families - policy and practice implications, an ARC Linkage Grant project funded by the Australian Research Council.
- 3. Young Carers: Their Characteristics and Geographical Distribution. Research project undertaken on behalf of the National Youth Affairs Research Scheme (NYARS), Department of Education, Employment and Workplace Relations
- 4. Analysis of the evidence about the costs and benefits of different policy options for supporting carers to ensure that they are able to continue with their care. This project is being undertaken for and funded by the NSW Treasury.
- 5. Active Ageing: Social, Civic and Community Participation of Older People and the Significance of Care-giving. Funded by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

The SPRC also has a number of recently completed projects on carers including:

- 1. 'Reaching Isolated Carers: Contacting Carers with Unmet Needs for Information and Support. This is an ARC Linkage project
- 2. Negotiating Caring and Employment: The impact on carers. This is an ARC Linkage project

The SPRC would be pleased to contribute to this inquiry into the *Better Support for Carers*. Please find enclosed a summary of our current projects, together with a list of recent publications and presentations. At this stage we are not in a position to make specific policy recommendations, but we would be pleased to provide further information on our research and publications.

We would also be very pleased to be invited to participate in the hearings for this inquiry and will make every possible effort to contribute.

Yours sincerely,

Bettina Cass

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Attachments:

- A. Project Summaries
- **B.** List of Publications/Presentations

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Attachment A

Project Summaries

1 Current ARC Funded Projects

Young Carers: social policy impacts of the caring responsibilities of children and young adults

Australian Research Council Linkage Grant: 2007-2009

<u>Chief Investigators:</u> Professor Bettina Cass, Professor Deborah Brennan, Professor Ilan Katz, Cathy Thomson (all at SPRC University of NSW), Professor Deborah Mitchell (Australian National University)

<u>Partner Organisations:</u> Carers NSW, Department of Ageing, Disability and Home Care (NSW), NSW Health, NSW Commission for Children and Young People, Carers Association of SA, Department of Education and Children's Services (SA), Department of Further Education, Employment, Science and Technology (SA), Department for Families and Communities (SA), Social Inclusion Unit, Department of the Premier and Cabinet, Children Youth and Women's Health Service,

Project description

In Australia, 347,700 young people up to age 24 provide care for family members with a long-term illness or disability; 18,700 are primary carers. This project analyses the circumstances and needs of young carers and care recipients and the cost and benefits of the care relationship. The project is carrying out primary research with young carers, their care recipients and with service providers and policy makers. It is also undertaking analysis of large-scale national datasets. The findings will contribute to policies for young carers, which is a national public policy priority. The expected outcomes are new evidence about the diverse socio-economic and demographic characteristics of young carers and care recipients, taking into account geographical location, carers of non-English speaking background and carers of Indigenous background, carers at schools, TAFE and in employment. The study will look at the costs of caring to young people's education, employment, earnings, health and wellbeing, as well as the benefits of their care to the recipient and the family. The findings will contribute to the development of supportive policies, programs and services, particularly with respect to education, training and employment.

Grandparents as primary carers of their grandchildren: A National, State, Territory analysis of grandparent-headed families - policy and practice implications

ARC Linkage grant: 2008-2010

<u>Chief Investigators</u>: Professor Deborah Brennan, Professor Bettina Cass (both of SPRC UNSW), Associate Professor Sue Green (Nura Gilli, UNSW) and Anne Hampshire (Mission Australia)

<u>Partner Organisations:</u> NSW Department of Community Services, Department of Families and Communities (SA), Mission Australia, Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, NT Department of Health and Community Services

Project Description

This unique collaboration between researchers, four government Departments in the Commonwealth, NSW, South Australia and the Northern Territory concerned with child and family welfare, and Mission Australia, uses innovative methods to analyse both the lived experience of grandparent-headed families and the policy framework that surrounds them. The project will analyse the circumstances and needs of grandparents and grandchildren in different formal and informal arrangements. It will include situations where grandparent care is an informal family arrangement, as well as situations that result from child protection or Family Court orders. It will provide a comprehensive audit of national, state and territory policies and identify gaps for the development of policies and services to promote the health and wellbeing of grandparents and children.

A large number of grandparents would meet the Inquiry's definition of carers as "individuals providing unpaid support for others with ongoing needs due to a long-term medical condition, a mental illness, a disability or frailty". This is the case whether the 'cared for' are considered to be either the parents of the grandchildren, or the grandchildren themselves. Taking responsibility for grandchildren is often a way in which grandparents provide support for their own children who have long-term medical conditions (including drug and alcohol dependence) and mental illness. The definition also holds if we consider the 'others' to be the grandchildren themselves, since the literature reveals that many experience physical, psychological or emotional disability due either to pre-existing conditions or to the trauma of family breakdown and problems in the parental home.

2 Other Current Projects

Active Ageing: Social, Civic and Community Participation of Older People and the Significance of Care-giving.

Chief Investigators: Bettina Cass, Trish Hill, Denise Thompson and Megan Blaxland

Project Description

This project is funded by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA). It involves an investigation of the links between the well-being of older people in Australia, and their participation in economic, social and community life. The study explores and analyses the key risk and protective factors relating to economic and social participation and active engagement in social networks of older people and their carers, with a particular emphasis on the role of care-giving in maintaining participation. Young Carers: Their Characteristics and Geographical Distribution. Research project undertaken on behalf of the National Youth Affairs Research Scheme (NYARS), Department of Education, Employment and Workplace Relations.

Chief Investigators: Dr Trish Hill, Ciara Smyth, Cathy Thomson, Professor Bettina Cass

Project Description

This project, undertaken for the National Youth Affairs Research Scheme (NYARS), involves a review of the Australian and international literature on the characteristics of young carers and ways to identify hidden young carers. In addition, the project provides baseline and up-to-date information on young carers. The analysis provides information on the social and demographic characteristics of young carers, estimating the number, proportion, type of care provided, and including significant trends over time. The project also undertakes geographical mapping of the national distribution of young carers at regional levels to inform the development of supports and services.

Analysis of the evidence about the costs and benefits of different policy options for supporting carers to ensure that they are able to continue with their care.

Time-line: 2008

Chief Investigators: Cathy Thomson, Professor Bettina Cass

Project Description

This project, undertaken for the NSW Treasury, involves a review and analysis of the effects of various policies and policy options with respect to providing support for carers, including assessment of the costs and benefits.

Attachment B

List of Publications/Presentations

3 Government Reports

• Australia, (2007), Report of the Carer Payment (child) Review Taskforce. Carer Payment (child): A New Approach. FaCSIA, Canberra.

Available from: <u>http://www.aifs.gov.au/institute/pubs/resreport16/main.html</u>

4 Published Reports

- Bittman, M., Fisher, K., Hill, P., Thompson, D. And Thomson, C. (2004), *Identifying Isolated Carers: Contacting Carers with Unmet Needs for Information and Support-Final Report for ARC Linkage Project*, Social Policy Research Centre, Sydney.
- Thomson, C., Hill, T., Griffiths, M. And Bittman, M. (2008 forthcoming) *Negotiating Caring and Employment – Final Report for ARC Linkage Project*, Social Policy Research Centre, Sydney.

5 Unpublished reports

- Cass, B., Smyth, C., Hill, T. and Blaxland, M. (2008), "More people should know what good jobs carers do!" The Costs and Benefits of Care: Considering the case of young carers Final report to FaHCSIA, Social Policy Research Centre, UNSW, Sydney.
- Cass, B., Hill, P., Thompson, D. and Blaxland, M. (2008), 'Active Ageing: Social, Civic and Community Participation of Older People and the Significance of Caregiving', Unpublished Draft Final report to FaHCSIA, Social Policy Research Centre, UNSW, Sydney.

6 Published Papers/Book Chapters

- Bittman, M., Hill, T. and Thomson, C. (2007), 'The Impact of Caring on Informal Carers' Employment, Income and Earnings: A Longitudinal Approach' *Australian Journal of Social Issues*, 42(2) p.255-272.
- Bittman, M., Fisher, K., Hill, T. and Thomson, C. (2005), 'The Time Cost of Adult Care' eIJTUR: *electronic International Journal of Time Use Research*, 2(1) p.54-66.
- Brodaty, H., C. Thomson, C. Thompson and M. Fine, (2005), 'Caregivers of people with dementia and memory loss: reasons for service non-use', *International Journal of Geriatric Psychiatry*, 20, 537-546.

- Cass, B. (2006), 'Care-giving and employment: policy recognition of care and pathways to labour force return', *Australian Bulletin of Labour*, 32, 3, pp 240-256.
- Cass, B (2007), 'Exploring Social Care: Applying a new construct to young carers and grandparent carers', *Australian Journal of Social Issues*, Special Issue on Paid Care: Now and in the Future, Vol 42, No. 2 (Winter), pp. 241-254.
- Cass, B., (2007), 'Using the social care framework to analyse research on young carers', *Youth Studies Australia*, 26 (2), 44-49.
- Fast, J., Bittman, M, Fisher, K. and Thomson, C. (2004), 'Making the Invisible Visible: the Life and Time(s) of Informal Caregivers', In Bittman, M. and Folbre, N. (Eds), *Family Time: The Social Organisation of Care*, New York: Routledge.
- Hill, P., Fisher, K., Thomson, C. and Bittman, M. (2007), 'Caregivers and Community Service Non-Use in Australia', In Paoletti, I. (Ed) *Family Caregiving of Older Disabled People: Relational and Institutional Issues*, Nova Science, New York.

7 Conference Presentations

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- Brennan, D., A. Hampshire, B. Cass, and T. Marchant (2007), 'Understanding grandparent care: policy and practice implications of grandparents as primary carers of their grandchildren in the Australian context', Paper presented at Centre for Research into Families and Relationships, *Extended and Extending Families Conference*, Edinburgh, June.
- Cass, B., and D. Brennan (2007), 'Grandparents as Primary Carers of Their Grandchildren', Paper presented at Australian Social Policy Conference, University of New South Wales, Sydney, 11th -13th July.
- Cass, B (2008) Understanding Grandparent Care: Policy and practice implications of grandparents as primary carers of their grandchildren in Australia', Paper presented at *COTA NSW Grandparenting Forum*, Sydney 7th April.
- Cass, B and Smyth, C. (2007) The Costs of Care/The Benefits of care: A precarious balance? Considering the case of young carers', Paper presented at *Australian Social Policy Conference*, University of New south Wales, Sydney, 11th-13th July.
- Smyth, C., Cass, B. and Hill, T (2008), 'Young carers in Australia: Combinations of informal and formal support services for people with a disability: Who bears the costs of care-giving?', Paper presented at the Workshop on Social Care (formal, informal and semi-formal) for people with a disability and frail aged people: Perspectives from Australia, Scandinavia, Canada and the UK, Social Policy Research Centre, University of New south Wales, Sydney, 18th 19th February.