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Dear Committee Secretary

I would like to make a submission to the Senate Select Committee on Mental Health that is relevant to the following terms of reference:

b. the adequacy of various modes of care for people with a mental illness, in particular, prevention, early intervention, acute care, community care, after hours crisis services and respite care;
l. the adequacy of education in de-stigmatising mental illness and disorders and in providing support service information to people affected by mental illness and their families and carers;

Family carers play a vital, yet often unrecognised and undervalued role in society. As formal structures of care do not provide all of the health care required to maintain persons with a mental illness in the community, the contribution of family carers is significant. Respite care services can assist these family carers in their role, yet little is known about this group's access to these services. Despite the fact that people with severe mental illness (SMI) in particular require significantly high levels of assistance, their family carers often have difficulties with accessing accurate information and adequate services, and are largely excluded in medical decision-making, largely because of the issue of patient confidentiality (Groom et al., 2003; Jeon, 2004; SANE Australia, 1998a; Winefield, 1996). An Australian national survey of 35 organisations found that the carers of mentally ill persons are rarely acknowledged by service providers and are inadequately acknowledged in mental health legislation and national policy statements that focus on informal carers (SANE Australia, 1998a). Recent research indicates that education is a priority for this group of carers to address gaps in their knowledge of mental illness and behavioural management and coping strategies, as well addressing lack of awareness of community support and respite care services (Ageing & Disability Department, 2001; Jeon & Madjar, 1998; Murphy, 1999).

Since inception in the 1940s and '50s in the UK (O'Brien, 2001; Stalker, 1996), the concept of respite care has been widely accepted and used throughout most developed countries. However, information on respite care services to date tends to originate from the care of frail elderly, people with dementia, people with intellectual disabilities, and children (Jeon, 1994; Jeon et al., 2005). Knowledge and availability of respite care in mental health is lacking as a basic service (Carers NSW, 2002; SANE Australia, 1998b), and scarce in the literature (Jeon et al., 2005; Murphy, 1999). UK researchers have reported similar problems in respite service provision for this population (Malcolm et al., 1998; Twigg & Atkin, 1994). In a review of 704 published papers on respite care between 1967 and 2002 we found 21 papers related to respite care for those with SMI and their carers (Jeon et al., 2005). No further papers on respite care for people with SMI and their carers have been found since 2002. Focusing on the past 10 years in particular, seven papers

examined respite care services specifically for this population. Most of them view respite care as an alternative to hospital care or as crisis intervention, which provided overnight placement, focusing more on patients than on carers (Breakey, 1996; Hoge et al., 1997; Sledge et al., 1996a and 1996b). Some, predominantly UK, authors discuss innovative models of respite or holiday respite care, specifically designed for those with a mental illness and their carers (Burns-Lynch & Salzer, 2001; Petch, 1996).

An exploratory field study was conducted within the South Eastern Sydney Area Health Service (SESAHS), Australia, covering the Local Government Areas of Botany, Randwick, Waverley and Woollahra, between April 2002 – August 2003. This study aimed to explore older family carers' needs for, access to and use of respite services when caring for people with a mental illness (excluding dementia), in the community; and to provide details of factors influencing respite care access for those carers, and strategies/recommendations to improve the services themselves. A purposive sampling strategy and data triangulation was employed. Information was obtained from face-to-face, in-depth interviews with 21 family carers aged 55 years or over, 26 mental health care professionals and 25 respite care service providers; through demographic questionnaires for all groups; via researcher field notes and memos; and document review. Demographic data were analysed using descriptive statistics. All 72 interviews, field notes and other documents were analysed using content analysis.

The findings reveal that current respite services are not adequate to meet the needs of mentally ill patients and carers. The unique aspects of respite care for carers of persons with mental illness are poorly understood. Major issues identified in the study include: limited respite care availability, provision, utilisation and flexibility—consequences related to service provision and access for mentally ill patients and carers; and unfamiliar meaning and lack of knowledge of respite care. The factors influencing respite care access for older family carers of persons with SMI are multi-dimensional. Health staff and respite service providers not only acknowledge there are structural gaps and inequities in respite services for this population group, it is accepted they each play a role in improving access and service delivery. The problems and issues related to the provision and use of respite care include: inadequate resource allocation to respite care services; health professional and respite staff's lack of awareness about respite care services and access procedures; inadequate promotion of respite to family carers; staff's negative attitudes towards the needs and experiences of family carers of persons with SMI; current service delivery models which are not always timely and flexible, needs-based or person-centred; and lack of collaboration in care provision.

Findings from documents relating to current respite care services in Australia

Main stream respite care services in Australia are provided by the following funding programs: Home and Community Care Program (HACC), National Respite for Carers Program (NRCP)/Commonwealth Respite for Carers Program, Community Options Program, Residential Respite Care, Aged Care Assessment Program, Commonwealth/State Disability Agreement and the Disability Service Program, Department of Veterans' Affairs (Aged & Community Care Division, 1996). Whilst these programs offer respite care to informal (mostly family) carers, regardless of the type of disabilities, anecdotal evidence from respite service providers and health professionals suggest most respite care services are accessed by frail older (over 65 years) people, either with physical disabilities or dementia/Alzheimer's disease. This situation was confirmed by the participants of the study. At the time of the study the available national databases such as the National Respite for Carers Program (Department of Health & Ageing, DoHA, 2002) and Commonwealth Disability Services (Department of Family and Community Services, 2003), did not produce statistics on the use of respite care services by type of primary disability. Therefore, the lack of a comprehensive database for respite care services, does not allow estimates of the level of need for respite care for people with SMI, although this information will be available in the future from the National Respite for Carers (DoHA, 2002).

According to the Ageing and Aged Care Division of the Australian Department of Health and Ageing (2002), substantial additional respite resources have been granted in response to the 1996 Respite Review

Report (Aged & Community Care Division, 1996) and the 2001 Gray Report (Gray, 2001). These include additional funding of $30.9 millions over four years by the Commonwealth Department of Health and Family Services in 1998, to extend the network of Carer Respite Centres and expand the capacity to deal with carers' identified needs. As well, the Department of Family and Community Services expended total funds of $150million dollars in 2000-2002 to target respite services for ageing carers of people with a disability. However most funds have been directed at residential respite services, brokerage for short-term and emergency respite, establishing and operating a respite care network, and on respite services for carers of persons with dementia. While this funding allocation is justifiable, the respite needs of carers of persons with SMI have not been met, despite the claim of government that funding is focused on more flexible care provision.

Recommendations include:

1. The level of resources for respite care—human, financial, physical, administrative and information resources—should be improved.
2. Staff should strive to empower the family carer.
3. Proactive promotion of respite care by mental health and respite care services.
4. Provide timely, flexible and appropriate referral to respite care.
5. Establish effective collaboration between mental health professionals, respite care service providers and carers.
6. Ensure that staff involved in respite referrals and provision maintain adequate skills and knowledge of respite services and caring for people with SMI.
7. Re-conceptualise the aims of respite services for people with SMI and their family carers.
8. Provide suitable environments for people with SMI during their stay at a respite care facility.

Given the large number of recommendations arising from this study, it appears that current respite services are problematic for family carers of people with a mental illness. Successful respite care services rely on the concerted effort of carers, health professionals and service providers. However, respite care alone cannot achieve the ultimate goal of relieving carers' burden and improving their quality of life: it needs to be provided in conjunction with other support services that aim to ease the caregiving trajectory. Given the uniqueness of the caregiving experience for families who have members with a mental illness, simply adopting respite care models suitable for other population groups may not be sufficient. All respite services must be appropriate to the populations they serve, otherwise their capacity to achieve desired goals will be limited and they will not be utilised to capacity. The findings of the project strongly suggest the potential to improve respite care service provision for persons with a mental illness and thereby, enhance their family carers' quality of life. No previous research has provided an in-depth examination of respite care in mental health in Australia (Jeon et al., 2005). It is hoped that these findings will assist mental health professionals and respite care service providers to better understand the respite care needs of families caring for a person with SMI.

(References)

Aged and Community Care Division. (1996) *The respite review report*. Canberra: Aust. Govt. Pub. Services: Aged and Community Care Division, Commonwealth Department of Health and Family Services.

Ageing and Disability Department. (2001). *NSW Government Carers Statement*. Sydney: Ageing and Disability Department, NSW Government.

Ageing and Aged Care Division of the Australian Department of Health & Ageing. (2002). *Access to respite care*. Retrieved August 18, 2003, from http://www.ageing.health.gov.au/carers/research/accresp.htm.

Breakey, W.R. (1996). Inpatient services. In W.R. Breakey (Ed.), *Integrated mental health services: Modern community psychiatry* (pp. 264-275). New York, NY: Oxford University Press.

Burns-Lynch, B. and Salzer, M. (2001). Adopting innovations--lessons learned from a peer-based hospital diversion program. *Community Mental Health Journal, 37*(6), 511-521.

Carers NSW. (2002). *Submission to NSW Legislative Council Select Committee on Mental Health: Inquiry into Mental Health Services in NSW.* Sydney: Carers NSW

Department of Family and Community Services. (2003). *Commonwealth Disability Services Census 2001*, Canberra: Commonwealth Department of Family and Community Services.

Department of Health and Ageing (2002) *National Respite for Carers Program Commonwealth Carer Respite Centres and Commonwealth Carer Resource Centres Minimum Data Set Draft Data Dictionary* Version 1.3. December 2002. Canberra: Commonwealth Department of Health and Ageing.

Gray, L. (2001) *Two Year Review of Aged Care Reforms*. Commonwealth Department of Health and Aged Care, Canberra

Groom, G., Hickie, I. & Davenport, T. (2003). *Out of Hospital, Out of Mind!* A report detailing mental health services in Australia in 2002 and community priorities for national mental health policy for 2003-2008. Canberra: Mental Health Council of Australia

Hoge, M.A., Davidson, L. and Sledge, W.H. (1997). Alternatives to acute hospitalization. In K. Minkoff and D. Pollack (Eds.), *Managed mental health care in the public sector: A survival manual. Chronic mental illness* (Vol. 4, pp. 191-204). Amsterdam, Netherlands: Harwood Academic Publishers.

Jeon, Y. (1994). Respite care for people with a chronic mental disorder and their caregivers: a critical review. *Australian Journal of Mental Health Nursing, 3*(1), 10-15.

Jeon, Y-H. (2004). Shaping mutuality as the core process of nurse-family caregiver interactions. *International Journal of Mental Health Nursing*. 13(2), 126-134.

Jeon, Y-H., Brodaty, H. & Chesterson, J. (2005). Respite re-visited: Critical review of respite care for people with a mental illness and their caregivers**.** *Journal of Advanced Nursing*, *49*(3), 297–306.

Jeon, Y., & Madjar, I. (1998). Caring for a family member with chronic mental illness. *Qualitative Health Research, 8*(5), 694-706.

Malcolm, K., Rowlands, P., & Inch, H. (1998). Assessment of respite needs for carers of persons with severe mental illness. *Psychiatric Bulletin, 22*(6), 354-355.

Murphy, B. (1999). *Literature Review Relevant to the NSW Carers' Framework*. Sydney: The Ageing and Disability Department and the NSW Health Department.

O'Brien, J. (2001). Planned respite care: hope for families under pressure. *Australian Journal of Social Issues, 36*(1), 51.

Petch, A. (1996). Cairdeas House: Developing good practice in short breaks for individuals with mental health problems. In K. Stalker (Ed.), *Development in Short-term Care: Breaks and Opportunities* (pp. 136-153). Bristol, PA: Jessica Kingsley Publishers.

SANE Australia. (1998a). *A long way to go: National survey of services for carers of people with a mental illness*. South Melbourne: Sane Australia.

SANE Australia. (1998b). *Planned respite care*. South Melbourne: Sane Australia.

Sledge, W.H., et al., (1996a). Day hospital/crisis respite care versus inpatient care: I. Clinical outcomes. *American Journal of Psychiatry, 153*(8), 1065-1073.

Sledge, W.H., Tebes, J., Wolff, N. and Helminiak, T.W. (1996b). Day hospital/crisis respite care versus inpatient care, Part II: Service utilization and costs. *American Journal of Psychiatry, 153*(8), 1074-1083.

Stalker, K. (Ed.). (1996). *Development in Short-term Care: Breaks and Opportunities*. Bristol, PA: Jessica Kingsley Publishers.

Twigg, J., & Atkin, K. (1994). *Carers Perceived: Policy and Practice in Informal Care*. Buckingham; Philadelphia: Open University Press.

Winefield, H. (1996). Caring for the carers of the mentally ill: A report on a forum. Carers' Association of SA, Unley, SA.

The materials presented in this submission have been extracted from the following papers:

- Jeon, Y-H., Brodaty, H. & Chesterson, J. (2005). Respite re-visited: Critical review of respite care for people with a mental illness and their caregivers. *Journal of Advanced Nursing*. 49(3), 297–306
- Jeon, Y-H., Brodaty, H., O'Neil Colleen & Chesterson, J. (submitted in December 2004). 'Give me a break' — Respite care for older carers of mentally ill persons. *International Psychogeriatrics.*
- Jeon, Y-H., Chenoweth, L. & McIntosh, H. (submitted in February 2005). Factors influencing the use and provision of respite care services for older families of people with a severe mental illness. *Ageing and Mental Health*.

Acknowledgement:
This project was funded by the Australian and New Zealand College of Mental Health Nurses (ANZCMHN) Inc. in 2002.
Project title: Respite care for people with a mental illness and their family caregivers
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Thank you for your consideration.

Sincerely

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15 April 2005