RESPONSE TO THE SENATE ENQUIRY INTO AGED CARE
28th July 2004

Introduction
This submission has been developed from discussions with clinicians who work in an Aged Care Psychiatry Service in NSW that provides clinical care in the hospital, community and residential care settings.

This submission will comment on:

- The extent of which residents with special needs, especially with dementia and mental illness, are met under current funding
- The adequacy of Home and Community Care (HACC) programs in meeting the current and projected needs of this group, and
- The effectiveness of current arrangements for the transition of this group of clients from acute hospital settings to aged care settings or back to the community.

This submission particularly relates to older adults with special needs such as dementia or mental illness. This group will be referred to as older adults with 'psychogeriatric' disorders as this is the most commonly used term. The majority of psycho geriatric patients are quiet elderly, over the age of 65 years and have multiple co-morbidities. However, it should be noted that a 'psychogeriatric patient' might occasionally be under 65 years of age and can be with or without cognitive problems and may or may not have concurrent medical disorders.

The submission will focus on three main areas of concern:

1. Residential aged care facilities
2. Community care, and
3. Transition care options.

1. Residential Aged Care Facilities

With regard to the concept of dementia specific aged care facilities, there is currently no policy or funding framework for concept facilities that are purpose built and managed for people with dementia and related co-morbidities that is severe enough to impact on their care needs. These types of facilities can provide quality care for those residents who otherwise are at risk of receiving very sub-optimal care in unsuitable environments. The lack of policy and funding framework has resulted in the following problems:

- Any facility can be labelled dementia specific whether it is purpose designed for dementia or not. This makes choosing the correct facility very difficult for carers and service providers.
- There is no ability for organisations wishing to build dementia specific facilities to easily access best practice guidelines for their design or functional management

- There is a marked shortage of purpose built dementia specific residential aged care facilities. The impact of this increases the length of stay of older adults in the acute hospital setting, creates the repeated transfer of residents between non purpose built faculties and increases safety risks for the individual residents, other residents and staff. The Occupational Health and Safely (OH&S) implications of this are very high and increasing; this also has a major impact on the aged care workforce shortages, training and recruitment problems.
- Purpose built faculties have no policy or funding incentives to be utilised for older people with the greatest need for that specialised environment. Therefore in practise they appear to be utilised for residents that solve facility management problems rather than the strategic needs of the older people with dementia. These problems are highlighted even more for people with the following special needs:
    - Non Alzheimer's Type dementia
    - People with Alzheimer's type dementia with moderate to severe challenging behaviours (e.g. those described by Dr H. Brodarty)
    - People with mental illness and early to moderate dementia, and
    - Older or younger people with acquired Brain Injury caused by e.g. alcohol, hypoxia, and intra cerebral bleeds. People with these special needs will often be refused entry to any residential aged care facility especially if the facility is dementia specific. Such people are at particular risk of adverse outcomes and face ongoing lack of tenure if they do succeed in accessing residential aged care accommodation. These people need both appropriate environments and funding structures that allows for an appropriate model of care. Although this group is only a portion of the total number of residents with dementia they pose severe challenges for residential aged care facilities. This group do not have the same opportunities for 'ageing in place" and therefore they and their carers are excluded from the benefits of this concept.
- The issues refered to above also prevent theses special needs group from accessing residential respite services.
- The increase focus on OH&S issues make current levels of violence within residential aged care facilities unacceptable. From a clinical service viewpoint this is leading to an increased refusal to accept older adults with current or a past history of challenging behaviours or any mental health disorder into residential aged care. This is both from an inpatient and community setting, and this is at times difficult not to interpret as being discriminatory.
- There is a marked lack of expertise in the general aged care workforce around basic care needs for people with mental illness or dementia. This is particularly concerning given that very high proportions (over 50%) of residents in any residential aged care facility will have mental health or dementia related problems.
- If the concept of 'ageing in place' is to be effectively applied to the special needs group referred to in this document, one of two options is required;

1. All new residential cage care facilities need to be designed around dementia specific principles, or
2. Funding structures allow a marked increase in residential aged care facility units to cater for this group. If this can not occur, then it needs to be questioned if the concept of ageing in place allows effective utilisation of any residential aged care units established for the special needs group.

- There will always be a small but significant sub-group of this special needs group referred to here that will need highly specialised care models and environments. These need effective co-operation between residential aged care providers and psycho geriatric and geriatric clinical services. This is likely to require different models for different sub-groups and creative funding solutions.
- There are very high rates of depression in residential aged care facilities. Despite funding the development of the "Challenging Depression" reference package to assist this, there is no implementation plan or funding. Subsequently, this good resource has had little uptake.
- People from Culturally and Linguistically Diverse (CALD) background have particular problems in residential care related to language and cultural issues. These increase with dementia or mental health disorders. This should be considered in funding structures and care models.
- There has been no released outcome from the review of the Commonwealth Psychogeriatric Unit programme. It is vital that more resources are directed to the target group of this programme. We would strongly support this funding being utilised in models that integrate with existing mental health services for the elderly; as well as having close links with aged care. It also is vital that such models encourage "core numbers" of staff with a 'psychogeriatric' focus to work together to develop professional skills and prevent "program drift" and wasted resources.
- For models of care expecting significant involvement and skills from general practitioners to work, there needs to be a major reconsideration of how GP's relate to residential aged car facilities. They are specialised environments that require clinical governance and specialised skills.

2. Community Services

- HACC was never intended to cover mental health – its primary focus was always frail aged and chronic disability and preventing premature residential care. HACC also does not take responsibility for a number of other areas though the Commonwealth has recently acknowledged a funding role in some areas of unmet need, e.g. post acute care or post hospital domiciliary services. (e.g. Compack pilot trial).
  - **Transitional Care**
    - Currently, patients who are discharged from 'sub-acute' facilities (such as ACP at Braeside are not eligible for the program). We need some form of transitional home support services as waiting

lists for mainstream services (even for Community Cared Care Packages (CACPs)) are very long. This could potentially prevent entry into residential aged care inappropriately, facilitate early discharge from hospital or prevent available hospitilisation.

- It is common for older people with psychogeriatric illnesses to not fit the eligibility criteria for most HACC or Commonwealth funded aged care services (community and residential). Eligibility criteria are biased toward ongoing functional impairment as a result of chronic physical disease processes and from dementia without significant behavioural and psychiatric co-morbidities.
- Older people with depression or mood disorders may have temporary incapacity or minimal functional impairment. Priority for most HACC services (**most notably Home Care)** is people with hands-on personal care needs. Instrumental Activities of Daily Living (more complex activities) like banking, shopping, arranging appointments, transport are not considered priority but are generally areas that older people with mental health problems/selective cognitive deficits require. There is no service that sees domestic assistance alone or socialisation alone as enough justification for acceptance of referral. Basically, it is getting harder to find a service that will not only meet the needs of a patient/carer but also accept the referral.

- Our patients commonly need socialisation and a home visiting service with flexibility. A case management and monitoring service for older people with mental health problems would be ideal (e.g like Community Options without the eligibility criteria necessitating justification of the person being at risk of residential care due to frailty). Aged Care Psychiatry clients are typically isolated, live alone and have minimal or non-existent family supports (family breakdown is a typical sequelae of long term, often untreated, psychiatric illness. There is only a home support service for people with dementia. Neighbour Aid service models are extremely restrictive and they rely on volunteers – almost to the point of being an unworkable resource for those with psychogeriatric problems (volunteer pool is always limited, unsustainable, can't do any transport or small jobs, etc).

- There is an inability of services to maintain, manage and monitor medication for the frail elderly and those with mental illness.

- There is a lack of clinical nursing support services as apposed to domestic support,

- There is a lack of streaming of service delivery causing confusion and anxiety to those receiving services. We support the CACP service delivery model but even these are inadequate in terms of hours offered.

- There is a lack of support services for the carer who may be frail and elderly particularly those caring for someone who is mentally ill. This

makes the carers vulnerable to developing a mental health problem themselves. All these issues need to be addressed.

- Lack of transport services. Community Transport is not flexible as it does not do out-of-area pick and delivery and the service is very restricted in the way they operate. There is no car service only bus.

- Day Care Centres are designed with the frail aged in mind. Dementia Day Care Centres typically are not designed to cater for challenging behaviours whether they arise from dementia or psychiatric illness. Dementia Day Care centres find it difficult to cater to the needs of all types of dementia. It is important to note that dementia is a not a homogeneous condition. We need more variety in day care options to cater for older people with mental illness (depression, anxiety, schizophrenia, etc). A social/rehab model rather than frail aged/respite model.

- As within residential care; those with non-Alzheimer's type dementias pose significant challenges. Consequently, services need to be funded and resourced to allow other models of care for these groups.

- Alternative therapies. Research is suggesting that alternative intervention treatments may be as effective as antipsychotics or other drug treatments for some conditions. These may be potentially less expensive and have fewer side effects than medications. Research and service model development is required to allow domiciliary support services and Carer Respite services to incorporate these therapies.

- Tailored packages of care such as CACPs have been very successful for the frail aged. Once again, psychogeriatric clients often do not fit the recommended eligibility criteria if applied strictly. They may not have huge personal care needs but a wide range of help is needed to maintain them comfortably and safely at home and **to stem remission of illness** – this is usually the aim of aged care psychiatry interventions – preventing relapse, rehabilitating as much as possible and sustaining or improving quality of life. Most HACC/aged care services are not based on a rehabilitative or supportive therapy model. Very few model themselves on a goal oriented, case management, therapy model. CACPs come very close to the ideal – though not all CACPs are run this way – there is wide variability. Mental healths CACPs for the elderly are needed.

- No service really provides the equivalent of hostel care in the home or extended evening services. This is particularly important for people without carers who have early dementia with features of mental illness or who require medication more than daily or in the evening

- Some older people with depressive illnesses will prefer to be in hostel environments offering structure, routine and company – despite having relatively independent functional profiles. These people are often discriminated against in favour of people with hands-on personal care needs, attracting more funding on a Resident Classification Scale.

- The newer Respite Services for people with dementia and challenging behaviours need to have the challenging behaviours arising primarily from a dementia. Challenging behaviours are not so much wandering – as psychiatric disturbances such as persecutory and other delusions, persistent paranoia, non-compliance and agitation. If the challenging behaviour is not secondary to a dementia, (but rather schizophrenia), then it is highly unlikely the service will accept a referral even if that person does have clinical signs of a dementia being present. Just as importantly "challenging behaviours" is often interpreted as any behaviour that the carer finds challenging. Whilst ideal with adequate resources, this appears to inhibit services focusing on clients and carers with the most need.

- Not all cognitive impairments can be classified as dementia, e.g. Vascular cognitive impairment; prior to developing dementia can require significant services to remain at home, but are not eligible for either dementia service or frail aged services.

- At-risk behaviours. The definition of what constitutes at risk and OH&S varies among services. Assumptions and stigma appear to exist. As, appropriately, OH&S issues become more prominent theses issues appear likely to increase. This is an obstacle to accessing services.

- Training of care workers. Whilst most receive training in provision of personal care, "uncomplicated" dementia and such like, very few receive training on depression, behavioural disturbance, delirium, and psychosis – common presentations in the elderly receiving community aged care services. There is a shortage of skilled staff that can train in these areas. Funding should both cover training and encourage training that utilises "aged care" and clinical service expertise.
- Accommodation advocacy- the ACHA service auspiced by Centacare is considered excellent by our social worker though it is purely an advocacy program - to help disadvantaged older people out of inappropriate accommodation or homelessness into Dept of Housing or other types. It does not have a support service component or enough funding to subsidise the extra expenses some psychogeriatric clients (homeless, financially disadvantaged) incur for life's basics – clothes, furniture, household items, etc especially when accommodation is found. Charities only give limited amounts. Creative solutions could significantly assist improvements in quality of life.

3. Transitional Care

Currently two particular groups of patients appear to be excluded from concepts related to transitional care. These are elderly patients discharge from acute care with resolving mental illness or significant behavioural disturbances from other causes (e.g. resolving delirium). Secondly, patients who are in settings categorised as sub-acute which includes patients with psychogeriatric rehabilitation or palliative care related problems. There would appear significant scope to apply transitional care principals to improve the

care of these groups; and probably in a more cost effective manner by avoiding inappropriate permanent residential care placement or avoidable time in hospital.

Conclusion

This submission has presented three issues. Firstly, issues related to the deficits in the availability of suitable environments for caring appropriately for older adults with dementia and behavioural problems and for those with mental health problems; concerns regarding the lack of trained staff who care for these clients and the impact of inadequate and inefficient methods of funding and funding allocations within residential aged care facilities. Secondly, the document highlights the inadequate community resources available to maintain older adults with mental health problems independently in their own homes; that resources are often inappropriate for their needs and the lack of social structure and support needed to compliment this option such as poor transport access. Thirdly, the lack of transitional care is noted as this care model is under recognised as a method to support older adults with co morbid mental health issues who are not acutely ill but who are unable to return home post acute care requiring a period of extended care and support.

Thank you for the opportunity to respond to the Senate Enquiry.
Please note that SANE Australia conducted a national survey of “Services for Older People with a Mental Illness” in 1999. This was complied by Dr Paul Morgan and Barbara Hosking and published in the Australasian Journal on Ageing, Vol 18 No 4 November 1999.

Reference

Brodarty, H., Draper, B and Low, L. F. Behavioural and psychological symptoms of dementia: a seven-tire model of service delivery. Med. J. Aust, 2003 178 (5): 213 – 234.

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