

The following individual submission to the Mental Health Senate Inquiry addresses particular terms of references as indicated, and with particular points raised in relation to concerns with the provision of community based mental health services and opportunities for community participation, with some points being specific to South Australia. It is based upon information from national reports and submissions, my experience working as a health professional and in the community services and also upon my experience as a family carer and in carer advisory groups.

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**(A) the extent to which the National Mental Health Strategy, the resources committed to it and the division of responsibility for policy and funding between all levels of government have achieved its aims and objectives, and the barriers to progress**

Whilst the National Mental Health Strategy has been considered an international benchmark and has facilitated the development from institutional to community based care, South Australia has stood out in the National Mental Health Reports for its continued reliance upon its stand-alone psychiatric institution including in the latest report (DHA 2003), although its closure was recently announced. SA has the highest in-patient bed numbers (DHA 2003) and mental health related hospital separations (AIHW 2005), and there are above average numbers of health professionals working in the sector when compared to other states, second only to Tasmania (DHA 2003). Conversely, the current provision of community based support services, funding to NGOs and community residential care is relatively low when compared to other states (DHA 2003) and seriously lacking.

In Australia, both the Mental Health Statement of Rights and Responsibilities (Commonwealth of Australia 1991) and the National Mental Health Policy (Australian Health Ministers 1992) developed a rights approach to services through the legislative affirmation of rights. The former statement includes;

“the right equal to other citizens to health care, income maintenance, employment, housing, transport, legal services, equitable health and other insurance and leisure appropriate to one’s age” (Commonwealth of Australia 1991, pg 1).

A current AHURI research report (Cooper & Verity 2004) on housing for people considered to have complex needs in South Australia shows that those with a mental illness were most likely (2/3rds) to be in unstable accommodation in the previous year. Nationally, people with a disability represent around one quarter of those receiving SAAP services but are less likely to be receiving support with financial and employment services (Psychogios 2004). Employment rates amongst consumers with a chronic mental illness are low, as only 6.5% of people with a mental illness are receiving support under the CSTDA are in paid employment (AIHW 2005). Whilst employment is the main assistance accessed for people with a mental illness under the CSTDA (AIHW 2005), such assistance is not readily available for people with a mental illness under the CSTDA in SA.

**(C) opportunities for improving co-ordination and delivery of funding and services at all levels of government to ensure appropriate and comprehensive care is provided throughout the episode of care**

The National Mental Health Strategy (NMHS) has placed enormous responsibility for mental health outcomes on the mental sector and there are more opportunities to draw in other sectors such as housing and employment in prevention and ‘recovery’ strategies, and particularly to address the stigma surrounding mental illness. At a national level, linkages are not strong between the Commonwealth State Housing agreement (CSHA), the Commonwealth State Territory Disability Agreement (CSTDA) and the National Mental Health Strategy (NMHS), and the 3<sup>rd</sup> National Mental Health Plan (2003-2008) has recognized the importance of other sectors however is still awaiting implementation. The National Action Plan for Promotion, Prevention and Early Intervention (2000) considers housing and other sectors as important, however when it comes to actual strategies for consumers and carers, other sectors are rarely mentioned. In terms of clinical care, problems continue to arise from coordination across private and public services at various health sector levels. Better integrated policy and performance indicators pertaining to service integration and cross sector activity and linked to clear strategies in commonwealth-state agreements, policies and plans are suggested.

Other state-territory agreements relating to disability NGOs have been less connected to the mental health sector in SA and SA does not report data to the CSTDA national data set collection (AIHW 2005). There appeared to be some dispute about mental health funds coming from the disability or home and community care programmes in SA, and mental health may be an area overlooked in such agreements or programmes. Although the CSTDA is meant to include funding and services for people with a mental illness, these funds are not made available to people with a mental illness in SA (Productivity Commission 2002). It is unclear from Productivity Commission reports what percentage of HACC funds are being targeted toward younger people with a psychiatric disability by state. Once again, standard performance indicators relating to provision of community based services for people with a chronic mental illness are required.

Home support such as that offered through CSI services is brokered through mental health services in SA, so that those people no longer connected to clinical mental health services but with an ongoing condition may no longer be eligible for assistance (SACOSS 2003) causing problems for ongoing community care, or where private services such as GPs are expected to draw in other services in care plans.

Many private boarding houses and residential facilities are playing a significant role in housing people with a chronic mental illness in South Australia and it has been suggested that such private services need to be drawn into support and service frameworks at a state level (DHS 2003).

**(D) the appropriate role of the private and non-government sectors**

Private services play a significant role in South Australia as indicated by recent AIHW (2004) data. SA has the highest rates for PBS/RPBS expenditure for GP services, non-psychiatric specialists and psychiatrists (AIHW 2004). Private psychiatric service provision was amongst the highest of all states and SA spent above average expenditure on private psychiatrists and had the

highest rates of mental health related prescriptions by private psychiatrists of all states (AIHW 2005), however spread of such professionals is obviously a barrier to access in addition to costs. Whilst GPs may play a crucial role in early intervention and treatment, particularly for common disorders such as anxiety and depression, many people with a chronic mental illness may have no regular GP particularly if they lack insight into their illness and better supported shared care programmes are required. Rising costs of GP services may be an obstacle for people with a chronic mental illness in receiving ongoing care.

Even if 'shared care' programmes between GPs and public mental health services are facilitated or people are encouraged to have a GP, problems may arise in the capacity of a GP to routinely coordinate treatment with families and other public or community mental health services, and to follow up such clients, particularly if users of services are transient as is often the case. This 'capacity' may be only partly related to GP workload and funding available to undertake this, as the coordination of services across public and private sectors is a major issue. The More Allied Health Services, Better Outcomes or Enhanced Primary Care package funding may have provided some inroads into making GP services more accessible (in areas where there are no GP shortages and workload is less of an issue), or more access to allied health staff, however the extent to which care plans have routinely involved family members and other public services (particularly non-clinical services) in planning and treatment is unclear, and some clinicians may see the coordination of non-clinical services as being outside of their responsibility. As the transition to community based care has been less supported by funding to supported housing and funding for NGOs in South Australia this situation needs to be rectified in order for integration to be more possible. The common situation of multiple care plans across public and private services or professional territory issues are obviously unhelpful to health outcomes and determining the 'appropriate role of private and non-government sectors'.

Whilst public services may be in a better position to be aware of the range of non-clinical support services available that may be incorporated into a care plans, there may be other issues with public services that are less likely to be encountered with private providers or NGOs. Many consumers may want a choice of provider, and have issues with the way confidentiality is dealt with within services, as well as stigma amongst health professionals (available in private or public services), and the fact that there is frequent staff turnover in public services making relationships difficult to establish and creating a lack of control over who has access to sensitive personal information. Also, families may be asked to provide sensitive personal information on an ongoing basis, but fail to have information provided by professionals due to 'confidentiality practices' or privacy legislation (somewhat against the aims of care planning), and individual circumstances may be more respected in private care arrangements. Having said this, it has been my personal experience that the services of private professionals have been more appropriate where people are already diagnosed and somewhat stable - in situations where a person has not already been diagnosed or a CTO has run out and is required again then private professionals have not played any role.

**(e) the extent to which unmet need in supported accommodation, employment, family and social support services, is a barrier to better mental health outcomes**

**Community Based Care**

Funding to NGOs only represents 1.9% of all mental health funding in SA compared to 9.3% in Victoria (DHA 2003) and is limiting capacity for ongoing community based care and opportunity for recreation, employment and housing support.

## **Housing**

People with a mental illness are overrepresented amongst the homeless (Dunn 2000, in Bryant 2004) and other health conditions associated with homelessness include respiratory disease, alcohol and drug dependence, suicide, accident and violence (Victor 1997, in Shaw 2004). In Australia, nearly a quarter of people connected to the Supported Accommodation Assistance Programme (targeted toward the homeless) have a disability and this group were more likely to require accommodation services and basic support and services than the overall client group (Psychogios 2004). Of this 'disability' group, the main reasons for seeking assistance included domestic violence, substance abuse, psychiatric illness, being a recent arrival to the area or having recently left an institution (Psychogios 2004).

The NZ Mental Health Commission (NZ MHC 1999; 8) claims that only a limited number of mental health services clients need supported accommodation as most clients live independently within the community. This need is not met by adequate funding in SA as the South Australian Parliamentary Inquiry into Supported Accommodation (2004) showed. Actual data on the numbers of consumers who may require a range of housing options needs to be better developed, beginning with the maintenance of records on housing by mental health services.

Australian Housing Urban Research Institute (AHURI) studies show that improved links between actual housing provision and mental health and community care services need to be made at policy and practice levels (O'Brien et al 2002). This 'working together' of services and across sectors is suggested in the national mental health strategy and plans and may not be pursued in state plans with strategies, outcomes and process indicators for this. Periods of hospitalization could be better incorporated into this support as one NZ study showed that 2/3rds of people from one mental health service said that hospital admission was crucial to them losing their homes in the first instance (NZ MHC 1999). Discharge plans involving liaison with housing and housing provision services to ensure that housing is maintained and that people have a home to return to are required.

## **Employment**

Opportunities for supported employment appear to be extremely limited in SA as is specific support for facilitating people into employment (refer to statement regarding the CSTDA above). More mental health literacy training for CRS workers, specific programs for people with a chronic mental illness are suggested. The recently announced 'work to welfare' scheme raises some concerns for people with a chronic mental illness who may either be on the disability pension or unemployment benefit. Specifically, some people with a chronic mental illness may prefer to be on the unemployment benefit than the disability pension (for reasons that may include a strong desire to work, a lack of insight into their illness, or stigma) but a main reason why these people may not actually be able to find work is stigma. Without raising the mental health literacy in the community and addressing issues of stigma amongst employment agencies, employers and the general community, attempts to employ people with a chronic mental illness are likely to fail.

### **(g) the role and adequacy of training and support for primary carers in the treatment, recovery and support of people with a mental illness**

One of the most important opportunities for support to carers is to have more professionals undergo training on the actual role that carers play in actual service provision and coordination, as well as on mental health issues to raise mental health literacy and reduce stigma. However, direct

carer support at the first onset of symptoms of illness, when misunderstandings about illness may occur, is particularly crucial. As mental illness involves a great deal of grief and loss as families come to terms with mental illness, this must be met with support services.

The most chronically ill may have no choice but to be connected to public mental health services where staff turnover may be high, further contributing to access problems, and placing more responsibility on family carers for coordination roles and actual service provision. Carers have a significant role in treatment and primary care, and due to the high staff turnover in public mental health services, it has been my experience that professionals sometimes actually rely upon carers for advice about treatment or there are indirect expectations about duty of care rather than vice versa. For example, in my family's experience a 10 hour wait in a casualty department was undertaken by a family member (carer) in full-time employment. This situation raises questions about duty of care - once a person is at the casualty department is it the responsibility of the hospital or of the family carer to maintain them there? Are workplaces flexible enough to support people who are working full time and may provide episodic support?

Once in community based services again, calls may be received from different key workers (due to staff turnover) pertaining to the family's opinion about the status of the person with a mental illness, particularly as it relates to the need to maintain or obtain a Community Treatment Order (CTO). Whilst the calls to family are welcome, they may be one-sided as a new key worker and Psychiatrist-in-training may be unfamiliar with the individual involved. Guardianship Board hearings are likely to include a Psychiatrist-in-training on rotation who has virtually no knowledge of the patient. In my personal experience as a carer, once it was agreed that a CTO should be allowed to expire, there appears to be little monitoring by services making it more likely that a CTO is actually required (and hence a 10 hr wait at the casualty department). The majority of service users may require minimal support (both informal and formal) to be maintained in the community, although there appears to be an 'all or nothing approach' – either a community treatment order (CTO) with a support worker or 'reactive' support without ongoing monitoring if a person is without a CTO. There is no balance between a CTO where services must intervene under law, and a supportive role by services working in conjunction with families, and this is an important issue as obtaining a CTO can be quite traumatic for individuals and their families. In these situations, from my personal experience private professionals have played no role at all.

Generally, there appears to be little pro-active contact by services to families even though carers are an important part of the service system, unless a relationship with an individual support worker has been established (difficult where staff turnover is high). Carer policies which are owned by and developed with professionals and carers should be in place, and include protocols for the pro-active contact by professionals to carers.

Policies and practices need to reflect on privacy legislation and what it means in the mental health context. It appears that in SA, privacy legislation is sometimes being interpreted to the detriment of consumers i.e. carers may not be involved in treatment plans due to the interpretation of privacy legislation and so opportunities for coordination of care with services are missed. The interpretation of or actual privacy legislation may also affect carer involvement in governance arrangements.

It must be recognized that it is often families who have a crucial role in bringing people homeless mentally ill people back into the fold of services, are deeply affected, and must have access to services in order to locate a relative who is homeless. However, privacy legislation seriously needs to be reconsidered in such cases in order to support these family members (including for

social security, homelessness, and other services such people may have links to). Homeless people with a chronic mental illness may not choose to be homeless if they are receiving the appropriate clinical support – the notion of independent choice and ability to care for oneself seems to be behind certain libertarian practices. Privacy legislation exacerbates the problem of homelessness as services may fail to communicate with either carers or other services involved with the homeless person (communication between hospitals in discharge planning and housing organisations, mental health services and housing organisations, mental health services and homelessness organisations). Crane & Warnes (2000) argue for the linking of information from services dealing with vulnerable people at risk of homelessness, however the same could be said of services interacting with families. It is often family members who are persistent enough to ensure that a mentally ill relative gets out of a situation of homelessness and receives appropriate treatment. Currently, if a carer attempts to contact a missing relative who is severely mentally ill, homeless and transient, there is no avenue through government departments due to privacy legislation, nor a national missing persons database. As a family member of a once homeless person with a mental illness, there is nothing more heart-wrenching than having lost a person to an illness, and then actually losing a transient and ill relative, only to have services unable to act when they are found as the person does not appear to be enough of a danger to themselves despite being without food or shelter and vulnerable to theft and abuse. Such situations could lead to a person being missing again for years (once this person was finally detained by police, diagnosed and received treatment they lived with the family until it pressured a key worker to ensure that appropriate housing was found). New legislation should consider specific instances of a chronically mentally ill person who is homeless and transient as current legislation (or the interpretation of it) is libertarian to the point of being completely uncaring towards the most vulnerable members of society.

**(i) opportunities for reducing the effects of iatrogenesis and promoting recovery-focused care through consumer involvement, peer support and education of the mental health workforce, and for services to be consumer-operated**

The value of consumer involvement may be questioned by professionals, especially given reporting measures for ‘health outcomes’ and the context of ‘evidence based care’ as defined by professionals and bureaucrats (see Tobin et al 2002). Simply being involved in service delivery or treatment processes may be invaluable for consumers and carers. Empowerment is part of the rationale for chronic disease self-management practice (CDSM), however consumer input into mental health services and involvement in CDSM may also have limited potential impact upon real issues for consumers and carers such as NGO advocacy, supported housing, vocation and recreation options, supported employment and ‘reducing stigma’ campaigns, and therefore may have limited claims to empowerment. In this environment, consumers and carers are more reliant upon advocacy NGOs which may have more capacity for responding to broader concerns of consumers and carers, building coalitions outside the health sector. However these are currently variably funded and may be financially pressured. Continuing ongoing support for consumer and carer participation mechanisms and advocacy organisations, and linkages between the two is important for consumers and carers voices to be heard.

In regard to the suggested potential of consumer and carer involvement in governance arrangements, perceptions about consumers’ and carers’ capacity for involvement may be an important barrier to actual involvement. If carers and consumers are to be more involved, it may require not only information and training but also strategies targeted toward professional

attitudes, as well as support for consumers and carers to be more involved. Such support for involvement may involve peer support. More 'consumer and carer consultants' already used in states (DHA 2003) with experience of consumer representation or familiarity of services could be utilized to facilitate broader involvement and for training purposes.

Currently, many of the same 'consumers' are continually used in the health sector in SA on advisory groups or governance structures, which without support from other service users or NGOs may lead them to be consumed by professional agendas. Such service users may or may not be receiving input from other users of services or feeding back to anyone on health service responses or informing others about implementation issues. Due to the frequent changes in health services or staff such consumers may be invaluable resources on the history of what is occurring in services and community participation structures. Broader involvement by community members should be sought in community engagement strategies, utilizing peer consultants.

**(m) the proficiency and accountability of agencies, such as housing, employment, law enforcement and general health services, in dealing appropriately with people affected by mental illness (and their carers)**

In South Australia, the South Australian Housing Trust in a submission to the Housing Management Council for the State Housing Plan (SAHT March 2003) has viewed deinstitutionalisation as leading to a funds shift from health to housing services, and "a significant capital cost for social housing providers". Integrated planning is suggested to ensure community integration and prioritization of service. However, this does not currently occur in the state. For example, South Australia currently lacks a plan pertaining to how mental health services will work with housing, such as the NSW Government (2002) 'Framework for Housing and Accommodation Support'.

The interpretation of or actual privacy legislation may affect accountability to users of services and their families. Privacy legislation appears to conflict with the National Mental Health Strategy plan of services working together, as well as national plans or state plans on service integration. Services dealing with people who are vulnerable to homelessness may not have processes in place to communicate with each other to prevent situations of homelessness arising. Public and private services in all sectors and across all levels of government should reconsider privacy legislation where a person is mentally ill and receiving treatment, at risk of homelessness, or actually homeless.

The absence of a national missing persons database should be developed as an urgent priority. The transient nature of many people with a chronic mental illness makes lodging a missing persons report within one state a futile exercise.

Police, prison staff, detention centre staff, and all government service staff who are likely to deal with people with a chronic mental illness all need more awareness of the symptoms of mental illness. Misunderstandings about symptoms of mental illness may prevent referrals to appropriate services in the best case, and in the worst case exacerbate situations and lead to imprisonment.

## **(p) the potential for new modes of delivery of mental health care, including e-technology**

Whilst appropriate for professionals, may be less important for people who are chronically mentally ill due to problems with access and costs involved. Some technologies may be more appropriate in country regions, in support to personal contact of peers and service providers.

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