mental health
community coalition ACT

26.03.2010

To:
Ms Grace Concannon
Secretary
ACT Legislative Assembly Standing Committee on Health, Community and Social Services
Via email

Submission to the Inquiry into Respite Care Services in the ACT

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The Mental Health Community Coalition ACT (MHCC ACT) is pleased to have the opportunity to provide input into the ACT Legislative Assembly Standing Committee on Health, Community and Social Services Inquiry into respite care services in the ACT.

Background

The Mental Health Community Coalition ACT (MHCC ACT) is the peak body representing the not-for- profit Community Mental Health sector in the Australian Capital Territory. Founded in 2004, the organisation promotes a diverse range of community agencies that support people recovering from a mental illness in the community. MHCC ACT works inclusively with all stakeholders to support the development of community-based services and promotes the interests of consumers, carers and not-for-profit agencies.

Mental illness is one of the disabilities, by which a person may qualify for respite care. A number of MHCC ACT members provide respite care services in the ACT ranging from respite-type crisis accommodation to a small number of respite beds only to some of the largest commonwealth and ACT Government funded respite care providers. MHCC ACT has consulted with some of these members in preparing this brief submission, but aims to represent the whole community mental health sector - consumers, carers, and service providers.

In addition MHCC ACT managed the ACT component of the Commonwealth funded, national “Building Capacity in Community Mental Health Family Support and Carer Respite Project” (hereafter Building Capacity Project). This project consulted with consumers and carers and worked closely with respite care services providers and other interested parties to consider barriers and explore innovative collaborative initiatives to deliver more and better respite care services. While this project unfortunately did not succeed in attracting more Commonwealth funding for respite care services to the ACT, it did succeed in establishing the blueprint for innovative partnerships across community sector organisations in the ACT.

Respite Care Services in context.

Firstly MHCC ACT would like to point out that reflecting on the Terms of Reference of this enquiry the Standing Committee has set itself a difficult task. Some respite care services in the ACT are funded by the Commonwealth Government, while others are funded by the ACT Government. This means not only that the total provision of respite care services in the ACT is a very large and diverse issue, but also that a substantial component of those services are effectively outside the control of the ACT Assembly. Funding for respite care services is provided from several different ACT Government sources as well, further adding to the fragmentation of the service area.

Secondly respite care services cannot be considered outside of the context of related disability, ageing, and mental health services, in particular supported accommodation services. Lack of access to appropriate supported accommodation and other community

based support services leads mental health consumers to reside in inappropriate accommodation or with family members. This directly affects the demand for respite care services by consumers and carers. This is particularly important in the case of ageing carers or carers, who are themselves unwell, where access to appropriate respite care services allow carers to extend the time they can care for their loved one at home, but in which it is also the case that lack of access to appropriate accommodation for the consumer forces carers to continue to care for their loved one beyond their capacity thereby creating an increased demand for respite care services.

Respite care services are an essential component of the mental health service system in the ACT and provide valuable support for consumers as well as supporting carers to continue to provide their essential support.

Auditor General's Report No. 3 of 2009: Management of Respite Services in the ACT

MHCC ACT notes that one of the reasons for conducting this inquiry is the Auditor General's report no. 3 of 2009. This report noted that '*there is scope for significant improvements to provide assurance that clients receive quality of respite services and on an equitable basis*'. In particular the report noted:

- A lack of documented procedures to assist staff in assessing individuals' eligibility and prioritising people to receive respite care.
- Deficiencies in supporting systems and operational practices in the government respite houses led to inadequate management of high-risk clients.
- Compared to the national average, access to respite services in the ACT had not increased proportionately to meet the growth in demand for services in recent years. DHCS did not have sound and robust processes to assess future support needs and was unable to provide support for all those requesting it due to increasing demand and limited funding.
- Accountability was lacking in that records management, client information systems, risk management and quality performance management were inadequate.
- Further, the complaints and feedback processes need to be improved.

The report also found that the cost per user in government respite services was significantly higher than in non-government services.

MHCC ACT finds that these concerns are important and recommends that this Inquiry require the government to report back on steps taken to address the issues raised and the progress in doing so. We also recommend that the Inquiry note the difference in cost of provision of services, which indicates that the ACT Government should target investments in improved respite services in the community sector.

Key issues for the Inquiry

1. Measurement of demand, data collection

It appears that current date collection does not provide a reliable evidence base for measuring demand for respite care services in the ACT. Fragmentation of funding sources, varying reporting requirements, and fragmentation of providers in the sector appear to be significant contributing factors to this. This fragmentation makes it difficult to ascertain with certainty which respite care services are actually available and what their capacity is. This makes the 'market' for services difficult to navigate for the consumer, as well as making it difficult to reliable measure demand, supply, or unmet need. Any single provider will often be delivering several different programs, funded by different sources, and targeting different client groups. This also means there is no clear picture of the level of duplication of services between different funding bodies or differences in availability of services for different target groups, some of which may be adequately served while service for others is woefully inadequate.

MHCC ACT members which provide respite care services consistently express frustration that demand for their mental health respite services exceeds their capacity to deliver, but some agencies also acknowledge that this is not the case for all respite care services in the ACT, whether because of over-supply, too restrictive criteria for access to certain programs, or simply because potential clients are not aware of the existence of a particular service provider.

2. Barriers to access

As described in 1 above, fragmentation of funding sources and providers makes the market for respite care services unacceptably difficult for potential clients to navigate. Workers in other services seeking to refer a client to a respite service often do not have sufficient knowledge of services available to make the best referral either.

The Building Capacity Project also identified resources for making proper and appropriate referrals as a key priority for ACT services alongside partnerships to improve coordination and improve service response

Other barriers to access identified in the Building Capacity Project include:

- Inability to physically access service entry points
- Denied access due to guidelines or their interpretation considering them ineligible
- Concern about stigma if they accessed services
- Lack of respite beds
- No services available locally
- Lack of choice and flexibility
- Complex and fragmented service environment
- No consistent whole of family approach

The Building Capacity Project also identified a substantial list of barriers to developing responsive services and workforce development gaps affecting quality and availability of respite services.

3. Program guidelines and criteria

Two essential problems have been raised by MHCC ACT members with regard to program guidelines and criteria. Firstly there appears to be an excessive focus in the respite care area on provision of crisis or emergency services. While these are a very important part of the service picture, such services are not able to respond to the need of mental health carers and consumers for ongoing and/or planned respite, which is vital to reducing the strain of living with or supporting a person living with a long term or chronic severe mental illness.

Secondly program guidelines are too often poorly developed or developed with a lack of understanding of the real issues and needs of mental health carers and consumers. Such guidelines may be unnecessarily rigid or so specifically targeted as to render large numbers of relevant carers ineligible. Combined with the complex and fragmented nature of respite care services in general this creates a significant barrier to access to services, renders respite providers unable to offer services to people in genuine need, and makes it nearly impossible to determine whether certain groups of carers are underserviced.

Mental health consumers and carers are a very heterogeneous group and require diverse and flexible respite options to support them to sustain a reasonable quality of life. Rigid program guidelines and narrowly targeted programs and funding create a significant barrier to the provision of flexible services and to the development of new services. This means mental health consumers and carers are underserviced and continually frustrated and stressed by problems of finding appropriate respite care. Similarly respite care providers are frustrated by the inability to assess and respond to consumer and carer needs rather than assess eligibility based on program criteria.

4. Gaps

Funding for, and therefore provision of, respite care services is unevenly distributed across sectors and even across particular population groups within sectors. Mental Health appears to be disadvantaged in terms of availability of funding and thus services compared to some other sectors. At the same time there is a case to be argued that need is comparatively high in the mental health sector because of the prevalence and long-term nature of mental illness. In particular, as argued above, access to appropriate respite allows carers of people living with mental illness to continue to support and care for their loved one longer than they would otherwise have been able to, reducing the pressure on the accommodation and support services which would otherwise have to assume those support and care responsibilities, and thus in effect reducing the pressure on government

funding for other much more comprehensive and expensive services. MHCC ACT would therefore argue that there are gaps in funding and availability of services for mental health consumers and carers.

A particular gap and area of need is respite care services out of hours and in weekends. The ability to on occasion attend activities, including social and recreational activities, in evenings and at weekends is a vital component in maintaining quality of life. Conversely being unable to ever participate in activities out of hours or on weekends is a major factor in increasing social isolation and marginalisation for carers of people living with mental illness. Tandem is a large provider of respite care services in the ACT and has recently been forced to significantly cut back on provision of respite services out of hours and on weekends due to insufficient funding to meet the high demand for respite services the organisation experiences. This has a significant impact on the service experience for users of Tandem's services and effectively leaves already disadvantaged consumers and carers worse off.

Another area which is of great concern to MHCC ACT is the impact of the ACT prison and in particular provision of necessary services for people in the prison who are living with mental health issues. MHCC ACT and its members have advocated for several years for the provision of appropriate mental health support services for people in the prison and for people exiting the prison. People may be detained in the prison on remand for extended periods under highly stressful conditions, which could result in an exacerbation of existing mental health issues or indeed in people developing mental health issues. Similarly the mental health of prisoners is proven to be poor compared to the general population. Within the suite of services which ought to be provided to prisoners and people on remand in relation to their mental health ought to be appropriate respite options, which would allow people in need a 'timeout' from the stressful prison environment. The crisis support unit within the prison does not cater for this sort of need, and there are not any other appropriate services at present.

Population groups identified in the Building Capacity Project as underserviced include:

- Young siblings
- Young carers
- Aboriginal and Torres Strait Islanders
- CALD population
- Forensic mental health

MHCC ACT appreciates the opportunity to provide input into this inquiry. Should Committee require further information on the content of this submission or other issues related to respite care services for mental health consumers and carers please contact MHCC ACT Policy and Sector Development Manager, Simon Viereck, on 6249 7756 or simon.viereck@mhccact.org.au.