

Answers to questions asked at the Senate Community Affairs Committee hearing on 1st April 2008 which required follow up

1. Client confidentiality and carers being kept out of the loop. Your organisational policy on this? The Victorian Mental Health Carers Network (Carers Network) does not have a written policy on issues of confidentiality however the Network has been very active in addressing this issue with the service system.

In relation to confidentiality issues the Carers Network has-

- Lobbied for the Chief Psychiatrist to look at the issues regarding confidentiality and the exclusion of family/carers
- Had a carer representative on the Chief Psychiatrists steering committee to develop guidelines on working with families
- Subsequent to this involvement on the steering committee, the Carers Network developed a brochure to inform carers about the guidelines (please see attached)
- The Carers Network developed a video in which two psychiatrists, one consumer and one carer discussed confidentiality (this video is now used by Carer Consultant's as a training aid for confidentiality issues)
- The Carers Network conducted a large forum in 2006 with the Health Commissioner, a lawyer and consumers and carers to discuss confidentiality issues
- The Carers Network worked with the College of Psychiatrists when confidentiality was discussed at the World Congress of Psychiatrists held in Melbourne earlier this year.
- 2. **Is funding for PARC programs recurrent?** Yes, PARC programs are receiving recurrent funding and those that are in the process of being set up in other parts of Victoria will also have recurrent funding.
- 3. How many other policy-coordinating or service overview bodies are set up in Victoria (so State bodies) which carers and consumers are involved in at the moment? And any other state government groups which carers and consumers are involved in at the moment?

As the Carers Network operates as the peak body for carers in Victoria we are in a unique position in this State where our member organisations, who all have a significant carer focus, work together, as part of the Network business, on issues regarding service design, service assessment, quality improvement, quality outcome measures and advocacy at service policy levels as well as relevant state and federal departmental levels.

Other bodies/organisations who have some involvement in policy-coordination and service overview at both a wider systemic level as well as with their own internal policy and service design structures, in relation to carers and consumers are; Carers Victoria, Arafemi Victoria, Mental Illness Fellowship, VMIAC, Bouverie Centre, Carer Consultant Network Victoria (CCVN), MIND Australia, Commonwealth Carer Respite Centres, Victorian Transcultural Psychiatry Unit (VTPU), Action on Disability in Ethnic Communities (ADEC). Eight out of these ten organisations are Carer Network members.

In terms of which other government groups carers and/or consumers are involved with would require a scoping exercise which goes beyond my capacity to answer comprehensively here, however carer and consumer representatives involvement, has occurred at various COAG Working Groups to overview the COAG reforms. Other carer/consumer organisations, which have representative involvement with government groups, are MHYFVic, various Child and Adolescent services and the Family Drug Help Group.

4. **Scope of unmet need with Respite Program?** Funding dollars were applied to Aged Carers, CALD and Indigenous 'groupings' of carers (prioritised in that order) this has meant that young carers, middle-aged carers and new carers engaging in the system, were not considered when tagging the funds to the aforementioned carers. As a consequence services have applied these funds *at their discretion and in assessing needs*, to carers who don't necessarily fall within the groupings the money was attached for.

It is also the case that the way in which the funding was apportioned, it was not taken into account that people who are currently engaged with services have preferences to engage with mental health specific organisations rather than services who are providers for the intellectually and physically disabled, (as these services were allocated the brokerage funds for respite or rather funding for mental health consumers and carers was bundled with funding for intellectual/physical disability funding).

Also there has been presumption about the manner in which the general community would engage with services. Carers who are perceived to be 'linked' into the service system already, may not in fact have any, or little, service provision provided to them. If a family member as a consumer has a clinical case manager, this does not mean it is a given that carers are being supported or provided service, due to their family members' involvement in the service system. It is also relevant that a carer who has some understanding of services and/or are seeking information about services at an initial stage, are more likely to seek information and service (particularly regarding needs for respite) from mental health specific providers, rather than other services.

Unmet need is also experienced due to allocated staffing hours, apportioned for respite service provision, within these intellectual/physical disability services, that is, a 1.5 position. The staff brief is in fact too large, for the time apportioned, to both fulfil the provision of respite for the intellectually and/or physically disabled clients and their respective carers, as well as (as I raised at the Senate meeting) these same staff requiring specific skill expertise, in the

assessment and understanding of mental health consumers and carers in providing meaningful respite service to this client pair, as opposed to the clients they have traditionally been involved in working with. Not withstanding that these services that have been assigned to distribute brokerage funds have been making efforts toward increasing their knowledge and understanding of service implications and design, for *mental health*. Essentially, brokerage funding needs to be isolated for Mental Health carers and consumers only because of the specificity of mental health circumstances and needs.

Unmet needs with the Brokerage Model: -

Development Funds having a 3-year tenure – the initial funding allocation to set up respite services is to be spent within a 3-year period. These services are expected to be self-sustaining beyond this time. There is a presumption that the availability of brokerage dollars, that consumers/carers can obtain to utilise these respite services, would maintain the existence of these services after the 3-year funding allocated. This is a very tenuous presumption to be made considering that the Mental Health sector, along with the broader community, are just familiarising themselves with the concept of *knowing* that brokerage funding is available for them to use in this way. What does this mean? If the brokerage monies are not applied for and used, will government presume that there is not the perceived need for respite for mental health consumers and carers? The model precludes a real comparative measurement between what brokerage funding is taken up by the community and what the actual need is.

To increase peoples understanding of what is available to them requires a considerable amount of time, resources and promotion that goes beyond a 3-year timeframe.

What is also crucial in terms of the nature of respite provision to mental health clients and carers is that to engage these consumers in meaningful respite which has benefits to them, that include applying principles of the recovery model, which involves issues such as, working with them to become resourceful, linking them in to the broader community, creating access with them and for them to other relevant services and creating a *relationship* with them that assists to make therapeutic and psycho-social changes in their lifestyle, often means evolving, incremental shifts that happen over time. With the increased emphasis on the provision of respite via brokerage funds, there is a leaning toward fulfilling emergency needs, which are equally as important but should not be at the expense of planned respite. Planned respite has its place in supporting the therapeutic benefits of assisting clients in maintaining a level of well being and function to sustain their continued involvement, and facilitate independence, in their community in an ongoing way.

Planned, ongoing respite, also greatly supports carer wellbeing in terms of being able to sustain their caring role.

5. What kind of access does your organisation have to the minister or the head of the department?

Historically we have been able to request meetings with the Minister and the Parliamentary Secretary: they have been responsive on every occasion. We have often met with the individual at the Department, who caries the carer/consumer portfolio and who is also available to consult with by phone. The Carers Network has had regular contact with senior policy officers in relation to examples such as, outcome measures and quality measures. It has also been the case that historically, we have consistently been given opportunity to take part in discussions of drafts in relation to carer policies and other strategies and policies eg. Cultural Diversity, consumer Action Plan. The Carers Network has also had involvement on Ministerial Sub-Committees (Consumer and Carer sub-committees) and the Ministerial Advisory Committee as well as other department working groups.

It is also currently the case of course that new departmental heads have more recently taken up their respective positions and new relationships with these individuals need to be developed for carer issues to be maintained and represented at the departmental level.