**Designing the new integrated carer support service**

**Draft Service Concept – Feedback**

**Part A – Feedback on ‘*Carer Gateway’***

* Whilst a welcome initiative, in current form information designed to assist mental health carers via *Carer Gateway* does not necessarily highlight contemporary law/policy in some instances. Under Mental Health Services, information is presented in question and answer style e.g. Can carers have a say in treatment? The information somewhat unhelpfully goes on to state: ‘…[a]s a carer you can make a valuable contribution to a person’s treatment and care. However, health professional are legally bound by confidentiality, and they cannot disclose information without the patient’s consent…’[[1]](#footnote-1) The various State and Territory Mental Health and Carers Recognition Acts do not appear, rather there is an accent on ‘Privacy’ laws via a further link, and reinforces previous MH law/policy that endorsed mental health *carer exclusion*.
* The telephone hotline available to carers during business hours via the *Carer Gateway* [www.carergateway.gov.au](http://www.carergateway.gov.au) is a welcome step (and a person answers). Please note service providers are listed only if they apply for registration at [www.healthdirect.gov.au/carer-gateway-registration](http://www.healthdirect.gov.au/carer-gateway-registration) and it is unclear whether Anglicare Victoria/St Luke’s has done so? I carried out several ‘spot checks’ and no listing appears in first 6 web pages under Find a Service> Mental Health> Respite> Macedon Ranges >Bendigo. A further and brief review of available information establishes that service provider information can be out-of-date/confusing e.g. *Loddon Mallee Commonwealth Respite and Carelink Centre*, appears on web page 2 of suggested ‘Respite’ providers for those in Macedon Ranges. However, a *Carer Support Services* worker (Bendigo) answers the phone, the connection between the two is unclear and likely to be difficult for individual MH carers in the community to grasp and particularly if they are under stress.

**Part B – Designing the new integrated carer support service – a draft Service Concept for the delivery of interventions to improve outcomes for carers**

The *Draft Service Concept* states its intention is to deliver interventions that improve outcomes for carers but ignores the obvious that outcomes will *only* improve with properly funded services and programs for mental health consumers (in Victoria). TANDEM (formerly the Victorian Mental Health Carers Network) recently launched *A Practical Guide for Working with Carers of People with a Mental Illness* and is available on their website at [www.tandemcarers.org.au](http://www.tandemcarers.org.au) The Guide states:

*[f]indings from the national consultation undertaken in 2015 to support the development of this Guide show that in current inpatient practice, in both public and private sectors, brief assessment and quick resolution of acute symptoms is the general focus of care. Reduction in length of stay, together with the under-resourcing of community-based services, has resulted in carers expressing an increase in their responsibilities.*

*Further findings showed that, within community-based services, staff training provided by public services and community-managed organisations (CMOs) in a partnership approach to service delivery is limited. Many staff express concerns regarding issues such as confidentiality. Information and* support is not keeping pace with responsibilities being placed on carers*.[[2]](#footnote-2)*

In my day-to-day work with mental health carers across the regions (Macedon Ranges, Bendigo, Campaspe, Gannawarra, Buloke) the issues discussed are likely to account for the often poor outcomes that mental health carers experience.

**Feedback**

* P12/13 Current Carer Support Policy Framework – The *National Carer Counselling Programme* is a worthwhile initiative BUT both mental health carers referred to the service by writer in past few months require counselling due to lack of meaningful services for their family members who both have a diagnosis of schizophrenia. The Australian Government’s system of direct payments to carers via social security in reality excludes many mental health carers. While it is a positive step to include links to the income support available via the *Carer Gateway* it does little to prepare many mental health carers for the barriers encountered when applying for such income support. Many mental health carers including elderly (often years past official retirement age), Indigenous, CALD, those living in regional/remote areas and those with disabilities encounter significant bureaucratic (and often technological) obstacles in dealing with Centrelink in its current form.
* P15 Carers risk being lost in care recipient focused programs – with Mental Health Respite soon to be transitioned to the NDIS either in part or fully, the predicament and burden of care for mental health carers is likely to increase in Victoria. At the time of writing most MH carers I meet are ill prepared for the introduction of the NDIS and lack basic understanding about how to register/gain access and/or knowledge about what services will be available if they cannot.
* P 16 Carers often have to provide simple information to many organizations – In Victoria the *Sctt Tool* has been available for years and in theory, I understand, was developed to overcome this issue. Use of the Tool appears to be avoided by the MHS system (even if it assists consumers and carers) because of a culture that chooses not to see the value. In the 3 main regions I work in, 1 community mental health clinic will complete, another does so occasionally and only with much prompting, the other refuses.
* P 17 Locating and accessing respite services is challenging – there are few residential places available for overnight Respite for mental health consumers if this is requested and it is usually expensive if available. Searching for Respite options via the *Carer Gateway*, in its present form, is not organized in a way that will be of much assistance, hopefully this will improve over time.
* P 18 A Shift towards prevention – seems difficult to aspire to for MH carers in the current crisis-driven MHS system with ever-decreasing services for consumers and only small pockets of success for a few MH carers. The entrenched stigma still directed at those with mental illnesses and their families and particularly those with low prevalence disorders remains on so many, many levels. It is difficult to see how this will change without an assertive programs aimed at those working within in the MHS system in particular.
* P24 Awareness – to improve outcomes for carers the *Draft Concept* needs to properly determine who it deems ‘hidden carers’ are? As an example and on the subject of ‘awareness’ it states: ‘[t]his is particularly relevant for the need to raise awareness to find hidden carers and reach Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse communities’. Australia is a multicultural society however, the *Draft Concept* does not strike me as a *culturally sensitive* document (particularly in relation to our First Peoples) and appears to default to an Anglo-Australian bias in its current form.
* P 25 Information – my experience is that MH carers respond to information delivered face-to-face and with explanation about how it can practically assist e.g. provide TANDEM brochure with explanation of the organization’s main functions - administration of Carer Support Fund - and how MH carers may gain access to and obtain this funding. Many MH Carers comment that best place for ‘Carer Information Packs’ to be made available is in acute mental health facilities and at the time they most need it!
* P27 Intake – Intake is ideally undertaken face-to-face in order to establish rapport and with follow-up undertaken via the phone and/or email as required. It shouldn’t be mandatory as some circumstances don’t require this (sometimes people just want a chat) and distance can be a serious barrier. A *Carer Support Needs Assessment* *Tool* (CSNAT) would be ideal – extend the current *Carer Plan* used at Anglicare Victoria to a CSNAT?
* P28 Education – Agree that targeted education, training and information works and highlight there is a clear need for this regarding NDIS. Not sure whether you can teach ‘resilience’ though?
* **P29 Design Considerations (Education)** – 1. MH carers could be encouraged to access education support by incorporating it with positive benefits as many live on low incomes e.g. massage before education session, petrol vouchers for those in regional areas etc. 2. Online education programs need to provide tangible benefits so design input from MH carers in the community, volunteers and peer workers is vital to ensuring such programs are relevant. A built-in mentoring capability for those participating in online education should be a design consideration and would promote health and wellbeing. 3. Include education programs for carers that are funded outside of DSS in the one integrated space e.g. *Carer Gateway*, otherwise information will not be consistently accessed and the problem continues.
* **P30 The evidence for peer support as an intervention** – the role of MH carers with ‘lived experience’ and who are employed of in the community-managed service setting as ‘peer support’ workers needs to be reviewed/challenged. In the clinical setting such persons are referred to as ‘carer consultants’ and the person is viewed as a professional and often has a tertiary education e.g. nurse, OT. In the community setting the term ‘carer consultant’ is not used for unknown reasons? This promotes a ‘class’ system for ‘carer’ workers and serves to reinforce a negative clinical/community-managed MHS system divide that is so unhelpful to all concerned and devalues the work of those in the community setting. Consequently, the MHS system assumes that those with ‘lived experience’ in the community setting are uneducated, unskilled and ‘only’ suited to face-to-face (informal) interactions with carers and which excludes systemic input etc? **Design Considerations** – 1. The carer ‘peer support’ model needs to be equitably designed to cover clinical and community services workers and adequately funded if considered to be of value and as MH carers in the community consistently feedback. *The Draft Concept* at times appears to hint that ‘peer support’ is considered to be something of a ‘volunteer activity’ for an already marginalized group (with often limited financial means). Why is cost identified as an issue here but not in regard to carer education mentioned above? If, for example, a quota system was introduced (i.e. 25% of all MHS system staff need ‘lived experience’) we could overcome this issue. 2. No ‘peer support’ should NOT be a service able to be accessed without structure or processes because it wouldn’t work and would be devalued as a concept.
* P31/32 Needs identification and Planning - the CSNAT would ideally become a foundation document for all service providers working with MH carers. **Design Considerations** 1. Goal-based planning could still work without a funded package if it provided solutions to problems and better outcomes for families. The funding of a future *Carer Advocacy Service* would be a vital part part of this approach and is desperately needed. 2. Self-assessment could form part of the future model but MH carers require input from skilled people e.g. nurses, OTs, social workers with ‘lived experience’ of the MH carer role.
* P33/34 A multicomponent intervention – this should be made available to all MH carers, however probably an impossible goal, so those with the highest need should be targeted. **Design Considerations** – 1. MH carers who would most benefit are those where the consumer has a low prevalence disorder e.g. bipolar, schizophrenia, serious clinical depression etc. 2. The criteria could also include: age of MH carer, vulnerability, region – and in addition to current diagnosis of consumer, admission(s) to acute inpatient unit etc.
* P 36 The need to support recipients of direct payments – this is particularly relevant with incoming NDIS and MH carers. Education and skills training is vital and NDIS is naturally biased towards most assisting people who already have the skills to manage packages.
* P38 Carer Mentoring – again a conflict between view of ‘mentor’ as a qualified person and a ‘peer led’ initiative as involving an unqualified person. This is very flawed thinking and needs to be addressed in the *Draft Concept.* **Design Considerations** – 1. A coaching program would be most effective at commencement of carer role e.g. after admission to inpatient unit and with ‘refreshers’ available on needs basis. 2 MH carers should determine when and if they require ‘coaching’ service, therefore can’t be mandatory.
* P39-41 Multi-component Support: Respite support services – most MH carers that do manage to access Respite services appear to receive benefit, however not equitably accessed within the MH carer community. In Bendigo and Macedon Ranges most MH carers who access the service are Anglo-Australians because service provision is biased towards uptake by this group. Concur with reasons for low uptake, however, targets for the regions are always met, area needs substantially greater funding and more EFT. A lot more could be said here! Often a ‘respite effect’ is what occurs. **Design Considerations** – a carer-directed model would work OK for those with adequate knowledge and skills BUT targeted support and education needed for many in order for self-directed model to work. Potential for some families, who may be severely strapped for cash/stressed due to caring role, to make unwise choices e.g. spend funds unwisely, face difficult choices around appropriate service providers. There is significant potential for some to receive poor quality services in a system that often negatively labels them and as The Guide pinpoints: ‘[w]here carers persist in the quest for information, they are often labelled as ‘angry’, over-involved’ or ‘difficult’.[[3]](#footnote-3)
* P42-43 Counselling – at present a 2-3 month wait appears the norm following referral,counselling is useful BUT again often the need arises due to lack of meaningful services for consumers. **Design Considerations** – 1. nothing beats face-to-face interaction, but phone/skype useful where this is not possible; 2. Can’t comment on the use of CBT in this situation but feel that a range of professionals prepared to utilize their ‘lived experience’ could be utilized.
* P44-45 Supporting All Carers – I will comment on Indigenous/CALD carers only. Both remain ‘hidden’ because most mainstream MHS systems are not culturally sensitive or designed to be responsive to their needs. Anglo-Australia concept of ‘family’ pervades and the MHS system relies upon the ‘medical model’ of mental health care that excludes input from many family members. Much more could be said here!!
* P45 Carers in Regional, Rural and Remote Settings – limited time to comment but agree with all challenges identified. Any future design should ensure that service provision is delivered by locals and ends the current reliance on outreach workers who spend much of their time travelling to and from large regional centres!
* P47 – Support to Access Employment – MH carers in regional and remote areas who may wish to return to work are severely disadvantaged because there is little employment available or significant distances have to be travelled – a serious problem and not sure how this will be overcome.

1. *Carer Gateway*, Mental health services, Can carers have a say in treatment?, P 2 of 4, www.carergateway.gov.au/mental-health-services [↑](#footnote-ref-1)
2. *A practical guide for working with carers of people with a mental illness, March 2016, Mind Australia, Helping Minds, Private Mental Health Consumer Carer Network (Australia) et al, p 8.* [↑](#footnote-ref-2)
3. Ibid [↑](#footnote-ref-3)