Mental Health Carers Australia

National Mental Health Carer Voice

Service Delivery Model For A Proposed New Carer Support Service System

A submission by Mental Health Carers Australia

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Contents:

Introduction: 1

Mental Health Carers: 1

The National Context 2

Advocacy: 3

Carer Feedback and Complaints: 3

Legislation, Standards, Compliance and Reporting 3

Structure of the Service: 4

Regional Hubs: 4

Local Delivery: 5

National Education and Training Initiative: 5

National Quality Assurance Framework: 5

Service Categories: 6

Awareness and Linkages: 6

Information and Advice: 6

Peer Support: 7

Education and Training: 7

Counselling: 7

Needs Assessment and Planning: 7

Coaching and Mentoring: 8

Respite: 8

Targeted Financial Support: 8

Further Support For The Reform Process: 9

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Introduction:

Mental Health Carers Australia (MHCA) is a member based national organisation representing people who support and/or care for a person with a mental illness. The state based member organisations have extensive connections with and understanding of families and carers of people with a mental illness. We commend the Australian Government's ongoing commitment to supporting carers and the Department of Social Services (DSS) initiative to improve access to carer support services.

MHCA supports the overarching intention of the integrated system to:

- proactively support carers earlier, and build their capacity to sustain their caring role;
- provide support where carers are in, or at risk of a crisis, which might adversely affect their caring role;
- provide support for carers to improve their long term social and financial outcomes; and
- support carers to participate in everyday activities such as education and the workforce.

And the objectives:

- to encourage and normalise uptake of services proven to help carers, earlier in their caring journey;
- to help and support more carers, than under current arrangements;
- to deliver a service carers will value; and
- to provide a service carers find easy to access and use.

In addition to these and consistent with the Statement for Australia's Carers[1], MHCA would add as an objective that carers should be acknowledged as individuals with needs beyond the caring role. Carer support services should extend to facilitate a carer's need or desire to discontinue their caring role due, for example, due to concerns about the carer's own health, wellbeing and safety.

Mental Health Carers:

While people who support or care for a person with a mental illness share common issues and experiences with other carers they also experience a range of factors unique to caring for someone with a mental illness, including:

- The stigma, guilt and isolation experienced are greater than for most other carers and create significant barriers to people asking for or receiving help from both formal and informal sources. Cultural factors may intensify these experiences. Carers are often deeply affected by adverse responses by neighbours, friends, school communities and extended family members[2]. The stigma experienced by carers and consumers in the mental health sector is also exhibited by mental health and other health professionals[3].

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[1] Carer Recognition Act 2010

[2] The Network for carers of people with mental illness, Differences and similarities, 2001

[3] Mental Health Council of Australia. 2011. Consumer and Carer experiences of stigma from mental health and other health professionals. MHCA, Canberra

- It is common for a person with a mental illness to have little or no comprehension that they are ill and to resent carer’s attempts to encourage them to seek treatment or support. It is also not uncommon for symptomology of mental illness to manifest as paranoia at acute stages with the person turning against the people who have been supporting them most.
- Families have always occupied an ambiguous space in mental health research and practice. They are seen either as burdened carers, as causing the mental illness in a family member, as acting to sustain the mental illness, or as contributing to relapse[4] However, utilising a person’s natural support network has also been shown to promote recovery and reduce acute episodes requiring hospitalisation.[5]
- The experience and nature of a mental illness is obscure and difficult to understand. The state of mind of a person with a mental illness is hidden. Carers and family members see behaviour and personality changes and emotional swings but cannot comprehend the internal experience which drives these changes. Unlike other carers who can more readily interpret and understand the experience of their family member, carers and families of people with mental illness experience great stress and confusion because they cannot see what is happening, don't know what to do or how to help. When difficult behaviour occurs, family functioning may be significantly disrupted and become crisis-oriented, sometimes resulting in conflict and breakdown. In some circumstances the behaviour can be frightening and bewildering for the carer and can impact on the carer’s physical, emotional and financial wellbeing.[6].
- The unpredictable and episodic nature of some mental illness, often with sudden onset accompanied by abusive behaviour, variability of treatment compliance, and potential involvement with the police and judicial system all contribute to the stress experienced by mental health carers.
- The high prevalence of substance misuse among people with mental illness compounds the grief and difficulties families face.

DSS have rightly acknowledged that “many carers do not identify as carers, they think of themselves as family or friends”[7]. This lack of identification can manifest as a barrier for families and carers accessing services as they do not see them as for them. MHCA encourages DSS to consider using language in the model which clearly reflects who carers are and makes it more likely they will recognise the relevance of the model and service system for them.

The National Context

MHCA strongly recommend revisiting of the National Carer Strategy and the Carer Recognition Act to drive national actions to improve carer identification and recognition across all caring sectors but particularly in the mental health sector. We recommend the research already captured in the *A Practical Guide for Working with Carers of people with a Mental Illness, 2016.*

The lack of detail regarding the extent to which state mental health services will engage with and fund carer services risks a nationally inconsistent outcome for carers of people living with mental health issues. It also raises the question of whether the state mental

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[4] Wydera and Bland, The recovery framework as a way of understanding families' responses to mental illness: Balancing different needs and recovery journeys, 2014

[5] Amir, N, Freshman, M, and Foa, E. B. (2000). ‘Family distress and involvement in relatives of obsessive-compulsive disorder patients’. Journal of Anxiety Disorder., 14, pp209-217

[6] The Network for carers of people with mental illness, Differences and similarities, 2001

[7] Delivering an integrated carer support service, Department of Social Services, 2016

health services will contribute funding to the regional hubs that will be specifically for 'mental health carers. Will the quality of face to face supports vary state by state based on the funds available at a state level for supports that are to form part of this model that are not federally funded?

An assessment of MHCA member organisations' clients over the past three years indicates that only 14 per cent of the services provided were to people caring for a family member with a diagnosis that would make them eligible for the NDIS. A survey conducted by Carers NSW in 2012 found that 60 per cent of mental health carers reported needing support, compared to 30 per cent of other carers. Mental health carers also rated their health and mental health significantly lower than other respondents in different caring roles. When put together these figures suggest that channelling significant state government finding into the NDIS will leave many families caring for someone with a severe mental illness without access to supports they badly need.

MHCA is very concerned that should, as is proposed, funding for the *Mental Health Respite: Carer Support* continue to be transitioned to the National Disability Insurance Scheme (NDIS) families and carers of people experiencing severe mental ill health, may no longer be able to access the services they need to maintain their caring role. This may occur where:

- The person with a mental illness is not eligible for the NDIS
- The person with a mental illness chooses not to engage with the NDIS. Many people with mental health issues do not seek services so it is likely, in the absence of assertive outreach, that many people with severe mental ill health will not engage with NDIS
- The person is eligible but the caring role is not fully acknowledged
- The support required by the carer is not accommodated by the activities funded through the NDIS.

Advocacy:

Is advocacy for mental health carers going to be funded at a national level? Establishing and maintaining strong engagement with the carers and translating that into clear information and advice to inform government decisions and process is important to ensure the objectives of the model are realised. Good public policy does not easily translate to good practice and outcomes out in the field. Strong advocacy is one way to support effective transition and implementation of the model.

Carer Feedback and Complaints:

Carer feedback should provide the base information for continuing to improve the service system. What legislation and structures will support the carer's rights to complain about a nationally funded carer service and where will they make their complaint?

Legislation, Standards, Compliance and Reporting

What is the status of state based carer legislation in relation to the reporting and compliance requirements of nationally funded carer service providers?

Will nationally funded carer service providers who support to carers of people with mental illness need to comply with the National Standards for Mental Health Services?[8]

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[8] Commonwealth of Australia. 2010. National Standards for Mental Health Services.

Under what legislation or service standards will nationally funded carer services need to comply?

Structure of the Service:

Regional Hubs:

MHCA supports the multi-level delivery structure, however is concerned that the regional service areas are not too large geographically, particularly in rural and remote areas where public transport can be poor. Transport and travel time can be a significant barrier to accessing services.

The model proposes that regional hubs will "*play a pivotal role in encouraging carers to seek support and services earlier in their caring journey"* including high risk cohorts using community links through such people as doctors, teachers, service providers and community groups. MHCA supports this approach, however, need more detail about how this is to be done in practice.

What mechanisms will be used to engage and communicate with the community sector? Is the intention to use the PHNs or to create another organisation? MCHA members' experience is that PHNs tend to be clinically driven which is not the service carers need. The size of some of the PHNs is enormous (for example one in the Northern Territory and three and Western Australia), making the critical engagement role pretty well impossible. If it is a new structure it will create another layer of complexity in the services system for carers and service providers to navigate.

Will regional hubs, on the basis of their population mapping, create separate pools of funds for carers based on the care needs of the person they are supporting for example health, aged care, disability, mental health carers? Or will funds be distributed on a geographic basis meaning that one region area may experience a shortfall while another has underspend.

One of the regional hub services listed is "*access planned respite and support services through collaboration with the NDIA*". As far as MHCA is aware, carer respite is not a service available through the NDIS. The shift of carer support funding to NDIS will mean the eligibility of carers to receive supports will no longer be linked to an assessment of the carer and their needs. Instead it will be entirely dependent on the NDIS eligibility of the person with mental ill health. The supports then available to carers will largely be based on enabling the carer to "have a break" by engaging the person with mental illness in an activity which frees the carer to do something else. Whilst this is a relevant way to enable respite it does not cater for the broad range of carer support needs.

Consistent with the Statement for Australia's Carers[9], carers have a right to participate in activities outside of caring. There is no guarantee of a coincidence in timing of activities available for the person with psychosocial disability with the needs of a carer to participate in employment, education or other activities, or to attend to their own medical appointments[10].

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[9] Carer Recognition Act 2010

[10] Anglicare, Carers doing it tough, doing it well, 2016

Will the regional hubs commission services from local providers? If they will, staff will require a high level of understanding about psychosocial disability and the issues which are unique to people who support or care for a person with a mental illness. Whilst there is some information on level of qualification required for different types of workers in the regional hubs, there is nothing on the broader workforce development required to competently support people caring for someone with a mental illness.

Local Delivery:

MHCA supports the proposal to deliver services in local communities, through local networks, however is extremely concerned that DSS will ”link to but not fund” the local delivery. Instead the model refers to “existing services and providers’ and “other government funded services”. With the current uncertainty about what federal and state government funding will be tipped into the NDIS it is unclear what services and for that matter which providers will continue to be available. Given this strategy is a key pin to the delivery of services MHCA strongly recommend that DSS establish what other government funding will continue be available to providers to enable them to facilitate local delivery and further recommend that Mental Health Respite: Carer Support funding continue to operate outside the NDIS. What mapping has been done to ensure that this proposal leaves no carers worse off than they currently are?

It is also a concern that local delivery, coordinated at a regional level will result in the highest concentration of delivery, particularly face to face support, being in regional centres not local communities. Regardless of the quality of online and centrally delivered services, some carers will need to access services in their local community. Whether that is because of poor internet access or skill, lack of transport, cultural considerations or simply fatigue. It is critical that service options are not a one size fits all, but are instead tailored to meet the needs of specific carers, for example, children caring for a parent with a mental illness or an extended carer network in an indigenous community. Programs of course would include carer education, peer support and counselling, but should also include programs that promote social connection and wellness for carers. MHCA member experience shows that low level interventions, such as support groups and retreats, can be very effective.

National Education and Training Initiative:

MHCA supports the National Education and Training Initiative. It believes though, that due to the unique circumstances for people who care for someone with a mental illness, some of this education and training will need to have a specific focus on mental health carers.

MHCA is currently undertaking an audit of existing online and self-paced education programs suitable for family and carers of people with mental illness and would welcome the opportunity to work with DSS on consolidating and updating existing resources and developing new curriculum to fill any gaps identified.

National Quality Assurance Framework:

MHCA support the development of a national quality assurance framework and strongly recommends that this framework includes specific standards relating to family and carers of people with mental illness.

One of the major stressors experienced by mental health carers is the lack of family focused practice across many sectors, particularly clinical services, which creates additional complexities for carers, for example, being excluded from consultations about treatment plans that they are expected to support. Preventative supports for carers would include addressing the shortcomings in various sectors that prevent carers from being treated as ‘partners in care’. MHCA has, in collaboration with a number other significant state and national organisations developed *A Practical Guide for Working with Carers of people with a Mental Illness.* The guide provides a step by step, standards based approach to assist organisations engage effectively with family and carers and so improve the outcomes for the person with the mental illness and the carer. It contains practical “how to” guides, case studies and checklists to assess performance. MHCA is currently undertaking a number of demonstration projects to test the implementation of the Guide and document the learning experience for use by other organisations. MHCA would happy to explore with DSS how the Guide might be used to inform the quality framework.Brandy11

Service Categories:

Awareness and Linkages:

MHCA is pleased that community education and awareness raising is a priority in this model but is concerned about the lack of detail about what and how the national delivery system will operate.

Changing community attitude is no easy task but worth while as it can strengthen the support carers can get directly from their community. Such a campaign would have to be long running and well funded. It would need to be multi-message as the information must be specific to the issues faced by different carers. The community information and education relating to a carer of a child with spina bifida would be vastly different to that relating to a child caring for a parent with schizophrenia.

It is also of concern that there is no detail about the topics which will be included. MHCA recognises that some information can be generic across all carers, however, suggest the topics should include targeted information

- focussed on removing the stigma associated with mental illness
- for employers and educators about how to better support carers at work and education
- for service providers about how better to engage particularly with carers.

Information and Advice:

MHCA supports the information and advice category of service but again has concern about the lack of detail relating to what the content will be and how it will be delivered.

Is it the intention to build the national information delivery portal onto the existing Carer Gateway? Feedback through MHCA member organisations indicates that people who care for a person with a mental illness have found the Carer Gateway does not work well for them. It is hard to navigate and is limited in the services it lists. Some of the services that come up on local searches have specific intake and/or eligibility criteria that mean they are not available to everyone and this information is not included in what shows up on the

Gateway. Information known by the existing Carelink provider has not translated to the website. How can this local knowledge be included in the website and how will the knowledge in the existing regional Carelink structure be protected when the system moves to the new ‘regional hubs’? It is a concern that if the current on line information system is not easy to use or accurate how will an expanded system work.

More detail is needed regarding the proposed curriculum, online delivery methods and the systems proposed to support carers learning. Information needs to be specific to a carers situation, for example, the needs of young people caring for an adult relative or parent and the associated stigma and fear of child protection or parents with adolescent children with emergent mental health issues who do not know what to do or think. As mentioned earlier, MHCA is currently auditing online and self-paced education and training packages currently available and suitable for people who care for a person with mental illness and would be willing to work with DSS in the development of this aspect of the program.

MHCA supports the concept of a national phone number to simplify accessing information, but, are unclear how this would work in conjunction with the already well established national mental health carers’ helpline. This is a well used and trusted service, currently operated by MHCA and supported by MHCA member organisations. Feedback from carers tells us they appreciate that the person on the other end of the phone understands what it’s like caring for someone with a mental illness, something that someone from disability or aged care is unlikely to understand.

Peer Support:

In line with the models proposal to “utilise rather than duplicate” (pg. 9) MHCA recommends using the SANE forums rather than creating another.

MHCA strongly supports the delivery of peer support on a face to face basis in people’s local communities. Peer support groups need access to advice and information from workers who understand their circumstances and preferable with a lived experience as a carer. Support groups should be based on the common experience of the carer (e.g. young carers) rather than generic carer groups.

Education and Training:

Please see comments relation to awareness and linkages and information and advice.

Counselling:

MHCA supports the concept of a national phone number to simplify accessing information, however, need to understand how this would work in conjunction with the state based helplines and national mental health carers’ helpline. Carers often contact helplines for advice about the mental health of the person they are caring for. The people who answer calls need be able to answer questions about consumers as well as carers. It is often a call about a consumer that is the ‘hook’ by which services encourage callers to self identify as carers and access carer services.

Needs Assessment and Planning:

MHCA supports the proposal to use an on line self-assessment tool which also provides suggestions for supports and how to access them. It is important, however, that access to information and anonymous counselling are not dependent on undertaking an assessment.

It is important for mental health and other carers, that they have access to phone help for immediate questions and needs that does not require anything of them.

MHCA also supports separate carer assessment and provision of funded services and supports for carers, who are often reluctant to spend resources on their own needs.

The model appears to be based on an assumption that the process of calling a national number for information and assistance, and then triaging through different levels until the carer gets local face to face support. MHCA member experience of operating carer helplines indicates that for mental health carers, the process is not linear in this way, but may take a number of phone calls over a period of time as crises escalate and abate, before the caller decides that they need more.

MHCA would also be interested to know:

> What is the progress on the development of the nationally consistent carer assessment tool?
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> What will the outcomes of the assessment mean for carers?
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> Will carers need to be assessed in order to access services?
>
> Can a carer be denied services based on the carer assessment?
>
> Can a carer incur a charge for services based on the outcome of their carer assessment?

See previous comments about the use of a national phone line and concerns regarding the web site.

Coaching and Mentoring:

MHCA supports the Coaching and Mentoring Model and reiterates the importance of ensuring the mentors are suitably experienced, preferably with a lived experience in the area of care they are working.

Respite:

As indicated previously in Local Delivery, MHCA is very concerned about the lack of clarity about what respite will be available outside the NDIS and carers eligibility for respite or any other supports in their own right. They are particularly concerned about the *Mental Health Respite: Carer Support* and respite for young carers.

MHCA would also like to know how the need for emergency respite will be assessed.

See previous comments about the use of a national phone line and concerns regarding the web site.

Targeted Financial Support:

MHCA supports the concept of targeted financial support to assist carers to continue in education or employment and in their caring role but would like more information about what this would consist of. They also encourage DSS to use the regional and local delivery networks to help identify carers who need this level of assistance.

Further Support For The Reform Process:

Mental Health Carers Australia and its member organisations are confident that by working with mental health carers, service providers and government, the experience of carers can be improved. Improving the capacity of carers in tern improves the experience and outcomes for people with mental illness. MHCA is grateful for the opportunity to provide this submission and is keen to work closely with DSS in this reform process in order to ensure the best possible outcome for people with mental illness, their carers and their families and are happy to support the process in any way possible. Should you want any further information or if MHCA can assist in any way please contact Jenny Branton, Executive Officer, 0417 532 344 or jenny.branton@mentalhealthcarersaustralia.org.au.