tandem

representing Victorian
mental health carers

Designing the New Integrated Carer Support Service

A Submission by Tandem Inc,
Representing Victoria's mental health carers
June 2016

About Tandem

Tandem is the Peak body for mental health carers in Victoria. We advocate for:

- ➢ Involvement in planning and care

- ➢ participation in system change

- ➢ support for families and carers

Tandem, formerly known as the Victorian Mental Health Carers Network, was established in 1994 and is the Victorian peak body for families/carers of people with experience of a mental illness or emotional distress. Tandem is a not for profit, community based organization. Tandem promotes and advocates for family/carer involvement in treatment and recovery of people experiencing mental health difficulties, family/carer participation in planning, delivery and evaluation of mental health services and appropriate support for families/carers. Our principal areas of work are: systemic advocacy, contributing to mental health policy development, information provision, development, delivery and promotion of family inclusive training for the mental health workforce, development delivery and promotion of training for families/carers in being effective carer representatives and administration of the Victorian Carer Support Fund on behalf of area mental health services.

Our mission is to ensure that the importance of the contribution, expertise, experiences and needs of families and other carers is recognised and that these needs are addressed. Families and other carers of people with mental health issues will be partners in treatment, and service delivery, planning, research and evaluation. The lived experience of families and other carers will be key drivers of policy and program formation at both the individual and systemic level.

Level 1/37 Mollison St, Abbotsford, Vic 3032
(03) 88035555   info@tandemcarers.org.au; www.tandemcarers.org.au

For information about this submission, contact Ms Marie Piu, Senior Policy Advisor, Tandem
Tel: (03) 8803 5501 marie.piu@tandemcarers.org.au

Table of Contents

Introduction

Tandem welcomes the Department of Social Service plan to re-design services that it provides to carers. While the strengths of current service provision are acknowledged, changes that look to ensure that supports to carers are sufficient to prevent the collapse of caring roles and to bring about the integration and strengthening of services are well due. Tandem is pleased to have the opportunity to provide some thoughts about the needs and priorities of the mental health carers amongst the target population.

The need for these changes is made more urgent by prospect of the increased amount of unpaid, family and community caring that will be necessary in the future, and the declining propensity of all demographics, except females over 55, to engage in unpaid carer work. Unless there is increased and better targeted support for carers, there will in the future be large numbers of unsupported individuals needing care, be they aged, with a physical disability, or with a mental illness. Those with the most complex needs are often those with a mental illness, and if they are not supported by family and other carers, the costs to the individuals and to Australian society as a whole will be very great indeed.

Tandem supports the Guiding Principles which are outlined in the draft Service Concept. There are several aspects of these principles that are particularly pertinent to the needs of mental health carers:

Principle 4 – Alignment The Commonwealth Government acceptance of the recommendations of the National Mental Health Commission Review of Mental Health Services[1], included a commitment to increased focus on mental health, to be delivered through the Primary Health Networks. To achieve alignment with this policy framework, DSS should ensure that the needs of mental health carers are specifically and adequately addressed in the new Service Concept, as this will directly impact on national improved mental health outcomes, including a reduction in the suicide rate.

Principle 6 – Equity of Access – There is evidence that mental health carers are disadvantaged in the access to carer payments and services in current services. This can be because the criteria for access

---

[1] http://www.mentalhealthcommission.gov.au/our-reports/contributing-lives,-thriving-communities-review-of-mental-health-programmes-and-services.aspx. Government response: http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-review-response

has been designed around physical disability, or because the carers of people with a mental illness are more likely to not self-identify, and are less likely to be directed to these entitlements, or because of the episodic nature of much mental illness. The new service concept will need to institute measures to ensure that carers of people with a mental health issue have equity of access to carer payments, allowances and associated services.[2]

Principle 10 - Innovative, flexible and tailored support – The needs of mental health carers differ substantially from those of other carers, due to the complex and often episodic nature of mental illness, and the disadvantage and hardship that frequently attends the presence of mental illness in a household. Mental health carers are the most disadvantaged group in the community, with the worst wellbeing standing of any cohort in Australian society.[3]

Tandem welcomes the Service Concept's focus on prevention, as meaning the sustainability of care, with its concomitant concern for carer 'burn out'. The members of Tandem, and feedback from the mental health carers of Victoria, indicate that family and carers mostly have a great desire to continue to support and engage with their family member/consumer as much and as long as necessary, but that with current levels of social support, and with the under-resourcing of the mental health system in Australia, the burden of caring is often intolerable and their best efforts are insufficient. This situation is very destructive and detrimental to persons with a mental illness and their families and carers. To achieve DSS's commitment to sustainable care, new integrated services will need to include measures that provide substantially more support, and more forms of support, than currently. Tandem's comments on how that is achieved in the eight service areas outlined by DSS follows:

Response to the Service Concept Design Questions

Awareness

What would be the most effective and efficient means of raising awareness for individual carers early in their caring journey?

A short note here re. the use of the word 'carer'. Often people who are caring for family and friends with a mental illness do not self-identify as 'carers' for the purposes of accessing services, and may indeed dislike the term ("*I am not his carer, I'm his mother*"). Often also, people with a mental illness may resist the idea that they have, or need, a 'carer'. This may be part of the difficulty in accessing 'hidden' carers, or in getting support to people who are entitled to it and would benefit from it. Tandem would recommend that all awareness services and activities should encourage the use of the language of natural relationships, and of the activities of the support, rather than stressing the term.

Tandem agrees that the difficulties discussed in the draft concept paper re. increasing awareness of carers and carer services in the primary health sector are real, and that in particular it is difficult to engage General Practitioners. GPs are, however, vital sources of information, and are very much part of the mental health system. Awareness of carers, and of the importance of families and carers to

---

[2] See Carers Victoria, Ben Isley, Invisible Care Report, CarersVic 2013
http://www.carersvictoria.org.au/Assets/Files/carers%20victoria_invisible%20care%20report_2nd%20ed_digital%20small_final%202013.pdf
[3] See Cummins et al, Wellbeing Index, Survey 17.1 report, Australian Unity, Deakin University, CarersAustralia, 2007
http://www.carersaustralia.com.au/storage/Wellbeing-Index-Special-Report-October-2007.pdf

mental health care, is a vital factor leading to improved mental health outcomes. Involving primary health practitioners in awareness activities will have multiple benefits. Given the policy directive to the Primary Health Networks to be actively engaged in mental health, this may be a possible way to reach carers.

The importance of identifying carers at the earliest opportunity cannot be too strongly emphasised. There are many reasons why hospitals, inclusive of area mental health services should be identifying carers and should be reporting against their systems in this area. It is of great benefit to a carer if a service acknowledges their role formally, and this identification will encourage them to seek and make full use of support services. From the point of view of the person with a mental illness, and of the service, the outcome will be better if family and carer are involved in the treatment, and are able to participate in the mental health system.[4]

Further to the note above that many carers do not identify themselves as 'carers' and will not seek support even if they need it, this applies especially to carers from Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse (CALD) backgrounds. Funding of support organisations specific to unique communities, and ensuring the use of translated and culturally appropriate materials, is an essential component of developing community awareness of the carer role and the existence of carer supports.

In considering support for young carers, to what extent should awareness be raised through schools and how could this best be achieved in a cost effective manner?

The importance of a prevention and early intervention investment is no more apparent than when we consider the vulnerability of children and young people who are often the 'hidden' mental health carers. Providing parenting and family based interventions to parents with a mental illness is clearly linked to improved outcomes for their children, producing a 40% reduction in the risk they will also develop mental health issues.[5] The Australian National Practice Standards for the Mental Health Workforce specifically identify the need to recognize and support the importance of carers and children in the recovery of the person with mental illness.[6] 21-23% of children have at least one parent with a mental illness and are at higher risk of developing mental illness, suicide ideation and attempts, and functional impairment than their peers, and appropriate early intervention programs need to be available to them.[7]

There are many reasons why awareness of young carers is important in early childhood and school systems, not least because of the impact on early childhood centres and schools of these young carers, and the impact that awareness of their circumstances and challenges will have upon their outcomes in the educational system, and on the functioning of those systems. Awareness of how to support young carers will improve the educational outcomes for this cohort. Currently, a family-centred model of practice is widely accepted in the early childhood sector for supporting children with physical and developmental disabilities, educators should be supported to employ similar practices to maximise the

---

[4] Leggatt, M, Familes as Partners in Mental Health Care 2011 http://www.carersvoice.com.au/assets/files/E-Bulletins/Families_as_partners_-_Leggatt_-_Summer_2011.pdf

[5] Goodyear, M et al, Standards of practice for the adult mental health workforce: Meeting the needs of families where a parent has a mental illness http://tandemcarers.org.au/images/Goodyear%20et%20al%202015%20(2).pdf

[6] Australian National Practice Standards for the Mental Health Workforce www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-n-wkstd13

[7] Medical Journal of Australia, 2013, www.mja.com.au/open/2012/1/1/intervention-programs-children-whose-parents-have-mental-illness-review

positive outcomes for children living with parents with mental illness.[8]

The knowledge and expertise of early childhood educators and caregivers can help to promote protective factors for children. Early childhood services provide support to these families by widening the definition of 'vulnerable children' to consciously include children of parents with a mental illness.

Building the capacity of early childhood educators to develop the skills and understanding of the impact of parental mental illness on children has been well documented as being critical.[9] Early childhood educators and care givers often feel inadequately trained to work with children and families experiencing difficulties associated with mental illness.[2]

Existing Federally funded programs, including the Children of Parents with a Mental Illness (COPMI) Program[10] are linked to valuable programs that work to increase awareness of young carers, and provide support through both the education and healthcare sectors. A brief survey of initiatives that could be built on to achieve DSS ambitions for integration and improved awareness of, support for and education of young carers would include KIDS MATTER[11], CHAMPS[12], Let's Talk programs, and the possible role that the Headspace[13] organisation could play in this area.

Information provision

While information is available through carer organisations today, as well as the Carer Gateway, would individualised recommendations be of benefit when carers are undertaking or receiving other services?

The 2012 Mental Health council of Australia **Mental Health Respite: Carer Support Consultation Report** noted that "while there is a great deal of information in the community for mental health carers, many are struggling to locate this information and remain unaware of the range of support services and entitlements available to them."[14]

Although the Carer Gateway is very new, it may well in the future provide a very valuable one-stop-shop that enables achievement of all three of the information provision objectives listed in the discussion paper. While it is now able to link people directly to information about entitlements, it currently struggles to link people to relevant, accessible, local, comprehensive service options. The points raised about awareness are also relevant to provision of information, and the same strategies could be employed.

Intake

When should intake be a mandatory process?

---

8 Sims M, Davis E, Davies B, Nicholson J, Harrison L, Herrman H, et al. Mental health promotion in childcare centres: Childcare educators' understanding of child and parental mental health. Advances in Mental Health. 2012;10(2):138-48.

9 Beardslee WR, Ayoub C, Avery MW, Watts CL, O'Carroll KL. Family Connections: An approach for strengthening early care systems in facing depression and adversity. American Journal of Orthopsychiatry. 2010;80(4):482-95

10 http://www.copmi.net.au/

11 Kids Matter focuses on the mental health of children, rather than children as carers, but the collaborative initiative between the education & mental health sectors could be built on https://www.kidsmatter.edu.au/

12 CHAMPS (Children and Mentally ill parents) is a suite of peer support programs for children of parents who have a mental illness or mental health issue. It is an initiative of the Eastern Health Area Mental Health Service in Victoria.

13 Headspace is an organisation founded to improve the mental health of young people in Australia, it has a school centred program, extending this may be a cost effective way to engage with the school sector.

14 https://mhaustralia.org/sites/default/files/imported/component/rsfiles/publications/Mental_Health_Respite_-_Carer_Support_Consultation_Report.pdf

The identification and assessment of family and carers in mental health services provides vitally important clinical data for those services, and assists in the achievement of optimum outcomes for the person with a mental illness. It is also a starting point for offering involvement and support for the family and carers. As noted above, the burden of caring for people with a mental illness can be very heavy and carer support can be planned and enacted from this service identification. This identification process also enables a service to determine whether a carer has an urgent need for a service.

Education

How can we encourage carers to access education support?

Tandem would support the discussion paper's contention that education, training and information for carers is the most effective intervention to support them, and would strongly advocate that the new integrated model of service provides maximum support to the continued and expanded provision of such training and education opportunities. Tandem knows firsthand of the value and benefit of such training opportunities for carers, and of how great a role they play in the better treatment of people with a mental illness.[15] Caring for people with a mental illness is a complex and delicate task, and there are many forms of training that make the illness more understandable, and coping with it much easier.

As we are aware, however, of the constraints on carers of people with a mental illness; the disadvantage, hardship, lack of mobility, and isolation, we would suggest that there are two important components to assisting people to access education support:

- The provision of general support, of respite and of counselling.
- DSS strong support to the continued provision of such education, workshop and peer-support group activities in the community and clinical sectors, funded and facilitated.

Peer Support

What are some of the tools or supports which could assist in delivering peer support to a broader base of carers in a cost effective manner?

Tandem is a partner in the SANE Australia facilitated Carer Forum, an initiative of MIND Australia. The evaluation of this online peer-support program seems very promising, as this kind of model would be very scalable, and would possibly answer some of the aims of broadening people's informal support networks and reducing isolation. Tandem, however, strongly advocates for the continued government support at all levels of carer support groups, in all their possible variety – men's groups, LGBTI groups, rural programs, ATSI support centres, craft groups, walking groups, gardening & sustainability groups as Tandem believes that social inclusiveness and community connection will be of most benefit to carers in reducing isolation and alleviating disadvantage.

Peer support groups which have been extremely successful in assisting mental health carers, and have previously been funded by DSS, are the groups facilitated and managed by GROW.[16] These have been evaluated.

---

[15] Carer participation Training: A course for Carers wishing to understand and engage with the Mental Health system, Tandem © 2010
[16] GROW Better Together, Carer Program, http://www.grow.org.au/carer-program/

How can a peer support model be designed which encourages carers to participate and remain engaged?

On-line forums and social media provide a means for carers to get information and to have questions answered, without having to actively participate.

Local *face-to-face* carer support groups enable carers to be engaged and participate. Such groups need to be resourced but produce enormous benefits. They are one of the most valuable conduits for education (see above), and for social inclusion and connection. The isolation of the mentally ill and their carers in our society is extreme, and well-formed groups are a mainstay against this isolation.

Should peer support be a service able to be accessed without pre-conditions or structure processes?

There are difficulties with non-structured carer support groups for carers of people with a mental illness.   Where service providers are supporting or resourcing a group, the groups will have a moderator. This is particularly the case where young carers are involved.

Needs Identification and Planning

To what extent do you think goal based planning should be used at the assessment stage of the process? Would a goal based planning approach be worthwhile?

See above re. the importance of identification of mental health carers as they are engaged with the health care system. The identification and needs assessment processes of services should be linked to the support, which would often include goal planning and similar.

More generally, see below under Counselling.

A multi component intervention, including Respite support service

Tandem would be extremely concerned to see the provision of Commonwealth-funded Respite services made available only as part of a limited multi-component intervention, with a high-needs entry threshold, and limited application. The 2012 Mental Health council of Australia **Mental Health Respite: Carer Support Consultation Report**[17] made recommendations about an ideal model of service for Commonwealth-funded respite services, these included:

- Provide a one-stop shop service delivery model which includes outreach services
- Offer client centred services, focussing on the individual needs of carers
- Strengthen collaborative and shared care practice
- Offer portability of support across services and geographic locations
- Include carer peer workers
- Offer a whole of family recovery focus
- Be culturally, age and gender appropriate
- Be available in urban, regional and remote communities
- Incorporate carer directed approaches to care
- Deliver comprehensive carer information for carers and mental health workers
- Address carers' physical & emotional health needs
- Move away from the language of 'respite'

Tandem supports these recommendations, and also believes that 'respite' should be offered as an adjunct service and not merely as a crisis response service.

---

[17] https://mhaustralia.org/sites/default/files/imported/component/rsfiles/publications/Mental_Health_Respite_-_Carer_Support_Consultation_Report.pdf

Counselling

As noted in the discussion paper, counselling is essential often in providing carers with much needed emotional support. It should continue as an available component of service delivery of clinical and community mental health services carer programs, and, as discussed above, in other services and social areas as appropriate (*eg.* schools for young carers). The Carer Awareness services discussed above need to break down the stigma about accessing supports like counselling. This is particularly the case for men, rural areas, and for some CALD communities.