

*Submission to Department of Social Services on the Draft Service Model for delivery of integrated carer support services.*

*16December 2016*

[*https://engage.dss.gov.au/a-new-integrated-carer-support-service-system*](https://engage.dss.gov.au/a-new-integrated-carer-support-service-system)

Our Vision

Wellways Australia advocacy vision is for inclusive communities that support needs and issues related to mental health recovery and social inclusion for individuals, families and community members.

Wellways Australia, incorporating Australian HealthCall Group, is a member-based, not-for-profit organisation that works with individuals and families whose lives are affected by mental illness and psychosocial disability. Wellways was established in 1978 by families who wanted to improve the services and information available to people affected by mental illness. Today Wellways is a leading national mental health and disability support organisation with services located across Queensland, Australian Capital Territory, New South Wales, Victoria and Tasmania. Our services span mental health, disability and community care, and currently reach more than 7,900 people each year.

The families that founded Wellways had a vision that people affected by mental health issues could be understood, accepted and have the opportunity to make a good life in the community. Today, too many are still missing out on the chance for a good life, with people affected by mental illness experiencing high levels of housing instability, unemployment, poverty, isolation and exclusion, poor access to support services and chronic physical illness.

Families and carers are an integral part of Australia’s health care system, providing unpaid personal care, support and assistance to aid the recovery of people with mental health issues.

The caring role has significant impacts on a person’s health and wellbeing. Evidence shows that mental health families and carers experience high rates of grief, trauma, stress, depression, anxiety and poor physical health. People also experience stigma, discrimination and social isolation resulting in the breakdown of relationships and disconnection from family, friends and community.

It is absolutely essential that families and carers receive social, emotional, financial and practical supports to sustain their caring role, while maintaining critical aspects of their life, their identity and personal journey. Wellways’ feedback on the Draft Service Model is informed by consultation with Wellways advocacy members and families, carers and consumers.

The new Integrated Carer Support Service is a powerful opportunity to further develop family and carer support services, providing a strong vision for the future and courageous goals to guide our work.

Wellways encourages further community feedbackand hopes that this submission stimulates conversations about Integrated Carer Support Services with our members, networks of families, carers, consumers and the broader community. For more information about this submission, please contact [advocacy@wellways.org](mailto:advocacy@wellways.org)

Rachael Lovelock and Cassy Nunan

Consultants, Carer and Consumer Advocacy and Leadership

# **Program Overview**

*In relation to the program overview, do you believe that the objectives, outcomes and delivery principals are appropriate for the services required to be delivered under each program? Do you believe that the services proposed to be delivered at a national, regional and local level are targeted appropriately?*

Wellways Australia appreciates the opportunity to provide feedback on the draft service model and is encouraged by integrated service model and its primary objectives. We believe this will allow families and carers to receive support in their own right which is self-determined.

While the service delivery model is targeted at early intervention we would like to clearly state that not all families identify with being a carer and therefore do not access support early in their journey. We would also note that the caring role is not linear and encourage the service model to clearly identify pathways and specific support at varying times throughout their caring role. We recommend that the Department of Social Services creates an integrated carer support service within the frame of the Carers Recognition Act.

Wellways supports the tiered structure of the service model providing support at a national, regional and local level. A critical aspect of this will be the identification of service gaps and tailoring of support to specific communities and diverse groups of people.

We applaud the inclusion of ‘peer support’, ‘needs assessment and planning’ and ‘coaching and mentoring’. These services are essential in supporting families and carers to explore matters such as:

* What has happened to me?
* What is a meaningful life for me?
* What are my needs and what support is right for me?

Exploring these questions assists families to develop resilience, and carers to sustain their own identify, wellness and supportive roles. This level of support helps people explore, identify and drawn on their own resources, communities and natural supports before accessing a service delivery response.

We see these elements of the draft service model potentially having the greatest impact on elements of personal recovery, and moving from the role of carer to family. These outcomes would include:

* Hope and optimism
* Connectedness with families and carers, with peers, and a sense of belonging within the broader community
* Through community capacity building, individual and peer support opportunities will be created for families and carers to develop more meaningful and contributing lives, through participation in society, education and employment
* Through peer support opportunities will be created for people to find their own meaning in their mental health experiences, to cope better, to be able to self-manage their health and wellbeing and caring roles, and be able to navigate service systems more easily.

This will have a significant positive impact for families and carers of people affected by mental illness.

We would note that the specific needs of mental health carers are not well considered and we encourage further exploration to understand challenges for mental health carers, such as stigma, social isolation, education and knowledge about recovery, not identifying as a carer and therefore not accessing services for many years. We also stress the episodic nature of mental ill health and advise that many mental health carers require support at different times, not just in times of crisis.

We also recommend specific attention to the assessment criteria; many mental health carers are deemed to be ineligible for service because the people they are supporting are able to shower themselves, dress themselves, feed themselves and meet other ‘tick box’ criteria. This is often referred to as an ‘under assessment model’ for carers. However, that same person may need support with social and relational recovery, finding a home and maintain daily living, accessing community and medical treatment and sitting with in times of crisis. None of these challenges are considered as issues in the assessment criteria.

# **Discussion Paper Questions**

*A key factor in the effectiveness of regional hubs will rely upon their ability to understand the local service landscape and identify service gaps. If you were operating a regional hub, how would you undertake service mapping for your region? How would you ensure that you had captured a complete view of the available supports for carers in your region?*

Wellways agrees that effective service mapping is required to ensure equitable delivery of carer support services by capturing the specific and individual needs of all. We strongly recommend that service mapping highlights the specific needs of Young Carers, Aboriginal and Torres Strait Islander communities, people from Cultural and Linguistically Diverse backgrounds, Lesbian, Gay, Bisexual, Transgender or Intersex (LGBTI) and Rural and Remote communities.

Wellways has experience in the Victoria Mental Health Community Support Services catchment based planning approach, this model supplements and supports the range of planning and service coordination mechanisms which already exist. It is informed by the ‘collective impact’ model which involves the commitment from service providers across all sectors to create a common goal to identify service gaps, highlight social determinants and deliver recommendations. Wellways is committed to consultation with families, carers, consumers, service users and community to produce information, knowledge, and impetus which can be distributed through funding bodies and organisations to inform equitable service delivery.

We recommend that service mapping:

* Identify service gaps and pressures
* Recommends and develops strategies to provide service that is accessible, equitable, self-determined and works in a holistic way to support individuals, families and community.
* Improve service coordination and integration.

We also note that community needs change over time and recommend that regular service mapping is completed to develop thriving individuals, families and communities.

*It has been identified that outcomes measurement will be essential for a future model. Outcomes measurement involves identifying how effective services are in achieving a particular objective. This commonly takes the form of a questionnaire which helps to assess aspects of the carers role. However, there will be a careful balance in measuring outcomes, whilst not placing undue burden on a carer to answer multiple questionnaires, particularly where they may be accessing more than one service. What are some ways that outcomes could be measured and these issues addressed?*

Wellways acknowledges the importance of outcomes measures and believes that the draft service model provides an opportunity to embed and improve data collection, program performance and evaluation tools.

We recommend that DSS look towards best practice in mental health outcomes and clearly define national indictors that:

* include co-design and co-production of outcomes measures between service users, service providers and funders
* include collection of different data sources such as (a) individual qualitative measures related to personal recovery outcomes and satisfaction, (b) high level systemic and community measures and (c) evaluation of socio-economic impacts
* align with an aspirational long term vision that reflects the underpinning values
* correlate with clear targets
* are derived from current research and lived experience expertise
* are measurable, reportable and indicate progress across key areas of reform
* drive ongoing improvement and reform of services
* support a more targeted, evidence-based direction of funds

Beyond outcome measurement, Wellways strongly believes that measuring progress according to the service delivery model must involve ongoing consultation and feedback from families, carers and consumers. This should not be limited to the experience of any one service, but the system as a whole.

*While this model will seek to help more carers, it will be important to ensure that quality services are being delivered. What would you view as the essential components of a future quality framework?*

## Community Inclusion

Providing support to family/carers and other natural supports promotes community inclusion. Mental health issues affect everyone who cares about the individual, especially family members (Goldman, 1982). While some of these impacts are positive (Ohaeri, 2003) a substantial amount of research finds that families affected by mental health issues engage in fewer social and leisure activities, experience financial strain and diminished quality of life, and have greater levels of personal and family distress (Lefley & Wasow, 2013) and stigma (Corrigan & Miller, 2004). These often result in exclusion and loneliness. A focus on community inclusion therefore requires us to consider the whole family, and challenges services to provide support that enables the development of mutually supportive relationships within families, and provides pathways for families and friends to engage in their own journey of recovery (Lovelock, 2015). Wellways recommends a stronger emphasis on community inclusion throughout the draft service model based on the principles set out in [*Well Together: a blueprint for community inclusion*](https://media.wellways.org/inline-files/Well%20Together_2%20May%202016_Final_Web_0.pdf)*.*

## Family and Relational Recovery

In recent years, concepts around recovery have increasingly influenced mental health policy and practice in Australia and throughout the English speaking world. Although recovery was originally conceived as an individual journey, it is increasingly seen as an inherently social process. A number of authors have proposed models of ‘family recovery’, which acknowledge that for many people it is impossible to separate their own recovery from the functioning of their family. 2 COPMI Gems.

*“The pressures and demands of my caring role directly impacted on my identity and life journey. My health, hopes, dreams and aspirations become secondary”*

Outcomes from the **Wellways Family Peer Education Programs** illustrate that family members in ongoing caring roles are personally impacted by grief and loss, poor emotional and physical health, financial concerns and stigma.

It is important that carers are supported in a recovery oriented manner, focusing on the caring journey as a separate but also parallel journey to their loved one. Supporting carers to identify with their own journey and reconnect to wellness and a ‘good life’ is likely to deepen the understanding of their loved one’s experiences, as well as their own strategies in moving towards recovery.

Wellways encourages the designers of the draft service model to deeply understand the experience of carers and support carers to return to roles as family members. We strongly advocate for individual and tailored support carers for carers to move towards their own recovery, and for services to be innovative in their service design. This support must focus in family and carers sustaining in their supportive role and a service in their own right, separate from individual packages for care recipients.

## Peer Workforce

## Wellways supports the draft service models inclusion of peer support, coaching and mentoring. Wellways encourages a stronger commitment to the ‘transformative value of bringing together the expertise of people with a lived experience alongside service expertise, to enable meaningful and active collaboration for people to change their recovery, leading to better outcomes’.

We recommend that the draft service model includes the provision of peer based services at a national, regional and local level. Research has shown that peer support is effective in the areas of suicide prevention, stigma and discrimination reduction and addressing physical health needs. To ensure family and carer peer based support are a fundamental part of the mental health service system, adequate funding and coordination is required to support the ongoing development and role of the peer workforce.

## Lived Experience Expertise

Wellways strongly recommends that a carer and consumer participation framework is embedded in the draft service model to ensure lived experience and leadership in all facets of the development, implementation, delivery and evaluation of the integrated carer support service. Co-design is a genuine approach to participation that recognises consumers and carers’ experience based knowledge offers a unique contribution to improving services that workers alone cannot provide. Co-design involves consumers, carers and family members working in equal partnership with national, regional and local service providers to ensure that those most affected by decisions made by the service are an integral part of the decision making process.

## Trauma Informed Care

A significant proportion of people with lived experience of mental health issues and their families have experienced trauma. Any responsive and effective service system must be trauma-informed, and we recommend that the Integrated Carer Support Services address how trauma informed care will be built into the draft service model.

# **Conclusion**

In summary, Wellways supports the Service Delivery Model believes that tiered support at a national, regional and local level will be positive to identify service gaps and tailor support to specific communities. We would note that the specific needs of mental health carers is not well considered and we encourage further exploration to understand challenges for mental health carers such as stigma, social isolation, education and knowledge about recovery, that takes into account those who don’t identify as a carer, and therefore not accessing services for many years, and the episodic nature of mental ill health. Wellways has specific expertise in providing evidence based, peer support and community education for mental health families and carers and would welcome the opportunity to be involved in further developing the model to incorporate family and carer needs in the mental health context.

# **References**

1 Well Together: A Blue Print for Community Inclusion: fundamental concepts, theoretical frameworks and evidence. Prepared for Wellways Australia Limited by Mark S. Salzer and Richard C. Baron from Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities (Philadelphia, PA. USA), 2016

2 COPMI Gems, Edition 23 Rhys Price-Robertson COPMI national initiative and Andrea Reupert PhD Monash University, 2016



**Wellways Australia | incorporating Australian HealthCall Group**

 276 Heidelberg Road, Fairfield Victoria 3078

[advocacy@wellways.org](mailto:advocacy@wellways.org) | wellways.org | 1300 111 400

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