

CARER ENGAGEMENT IN RECOVERY-ORIENTED MENTAL HEALTH CARE

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About Mental Health Carers Voice

Mental Health Carers Voice (MHCV) is the Peak Body for Mental Health Carers in the ACT. MHCV actively engages with mental health carers to have their voice heard and create positive change in the sector through individual and systemic advocacy. The Mental Health Carers Voice Advocacy and Policy Advisory Group (APAG) provides a guiding voice for our Mental Health Carers Voice Peak Body work. APAG is made up of mental health carers and provides Mental Health Carers Voice with significant input. APAG regularly consults mental health carers to understand current problems and major concerns within that community.

MHCV has written this position paper to show the need and benefit for carer inclusion in recovery-based models, and how this fits with the Triangle of Care. We also offer a series of recommendations and tools to help both inpatient and community mental health services in the ACT implement these changes.

Definitions

Carer:

- *The Australian Carer Recognition Act 2010 defines carers as people who provide personal care, support and assistance to people with disability, medical condition (including terminal or chronic illness), mental illness or frail age.*

Mental Health Carer

- *A mental health carer is a person who provides regular and sustained informal care to a care recipient whose main health condition is a mental illness (Diminic, et al., 2016).*

Recovery:

- *Recovery is defined as being able to create and live a meaningful and contributing life in a community of choice with or without the presence of mental health issues (Department of Health and Ageing, 2013) (Mental Health Coordinating Council, 2018)*

WHY RECOVERY-ORIENTED MENTAL HEALTH CARE?

Recovery-oriented mental health care is being increasingly adopted as a preferred model of care by serviced providers. The term “recovery-oriented mental health care” refers to “the application of

sets of capabilities that support people to recognise and take responsibility for their own recovery and wellbeing and to define their goals, wishes and aspirations.” (Department of Health and Ageing, 2013). Recovery-oriented mental health care is strengths based, and focuses on:

- Lived experience and sense of self
- Building skills and setting goals
- Building connections with peers and community
- Taking responsibility and control
- Hope and optimism for the future

Recovery does not propose that there is a “cure” for mental health issues, but rather that it is a process by which consumers can move to a place of better health and function on their own terms. Models accept that recovery is not linear and consumer journeys may be complex.

Recovery models also acknowledge the importance of social networks and supporters, particularly carers, in helping consumers to recover in the community. Some ways that carers may participate in recovery include:

- Emotional support to maintain hope
- Practical support like transport to and from peer support groups
- Assistance with paperwork to maintain connection with services
- Participating in family therapy to improve communication and problem solving
- Learning strategies to support their person to manage their condition at home
- Participating in psychoeducation to recognise signs of deterioration in the consumer
- Supporting the consumer to build skills

Because of this expectation of carers to participate in recovery-oriented mental health care, it is critical that frameworks are developed to include carers in mental health service systems. To realise the goals of consumer recovery, recovery-oriented services must recognise and support the role that carers play.

What are carers' current experiences of recovery?

Carers may play a significant role in a consumer’s recovery journey, but there are currently barriers to participation in many mental health services. Margaret Leggat (in McMahon & Hardy, 2010) summarises that we have extensive evidence to support the inclusion of carers and families as it produces better outcomes for consumers:

“Briefly summarised, the evidence reveals:

- *a reduction in relapse rates (up to 20%) – resulting in a reduced number of hospitalisations*
- *better adherence to medication*
- *reduced psychiatric symptoms*

Further research studies show other significant outcomes, such as:

- *improved social functioning of the consumer*
- *increased employment rates*
- *increased involvement in community*
- *reduction in the burden experienced by family carers*
- *improved relationships between family members, including improved relationships with the consumer*
- *cost effectiveness*

These improved outcomes align with the outcomes sought in recovery models, particularly where consumers can move towards a more independent, connected lifestyle.

However, carers need to be supported and enabled in their role to produce these outcomes. In Hungerford & Richardson (2013), a small group of local carers indicated that they felt that clinicians were pushing for consumers to be in the community and independent under the Recovery model, without communicating with or supporting carers. Carers felt that under the new model:

- They did not have adequate support or knowledge “...to actually be useful in supporting Recovery”.
- They had less right to information
- They had more caring responsibilities
- They would like more training
- They felt that the lack of communication with carers ultimately went against the recovery of the consumer – “Whenever I go to the [acute inpatient unit] and see the word ‘Recovery’ in big letters it actually makes me feel rather ill because I think it’s bitterly ironic ...”

This demonstrates how carers currently find themselves excluded in recovery-oriented services and feel unable to assist the consumer’s Recovery journey. Despite these difficulties, carers in this study “all expressed a willingness and commitment to supporting the Recovery-journey of the consumer, and working alongside health professionals as co-workers”. They suggested solutions such as routine face-to-face time between treating professionals and carers, psychoeducation sessions and a dedicated clinician to work with carers in the service to support them.

THE TRIANGLE OF CARE

The Triangle of Care model includes consumers, their carers and health professionals in a three-way partnership (Worthington, Rooney, & Hannan, 2013). There are 6 standards in the model, which are:

1. Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
2. Staff are ‘carer aware’ and trained in carer engagement strategies.
3. Policy and practice protocols regarding confidentiality and sharing information, are in place.
4. Defined [staff] post(s) responsible for carers are in place.

5. A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.
6. A range of carer support services are available.

Carers are often the person who knows the consumer the best and can provide services with insight into their treatment history, cultural needs, dietary requirements and more. Without this insight, treating professionals may implement treatments or conditions that are not ideal for the consumer, leading to feelings of disempowerment, contrary to the goals of recovery. With carer involvement, as facilitated by the Triangle of Care, staff can better

understand what factors will help consumers to participate in their recovery, and the carer can actively support the consumer's journey. To understand the importance of carers in treatment and recovery, professionals should remember that carers:

- Knew the person when they were well, and hope they will be well in future
- Often know what treatment strategies have worked in the past
- Often know how medications have impacted the person in the past
- Are most likely to notice early signs of change in the person's health
- Can facilitate continuity of care as the person moves between services or is discharged

The Triangle of Care model, when well implemented, will align recovery-oriented care and language, and carer supports such as identified carer liaison staff, psychoeducation, and connection to local carer support services (Hungerford & Richardson, 2013).

This model has been implemented in several pilot projects in Australia which have sought to implement *A Practical Guide for Working with Carers of People with a Mental Illness* (Helping Minds and Mind Australia, 2016). The *Practical Guide* incorporates the Australian Government's *National Framework for Recovery-Oriented Mental Health Services* (Department of Health and Ageing, 2013) and the 6 Triangle of Care standards (Worthington, Rooney, & Hannan, 2013) into a series of Partnership Standards with self-assessment tools and suggested strategies to meet them. One pilot in the Perth Metropolitan region, conducted with Helping Minds, examined the effectiveness of implementing *A Practical Guide* using a co-design model in four metropolitan inpatient adult mental health services and four adult community clinical mental health services (Lund & Stewart, 2018). Positive outcomes included:

- Increased staff awareness of the importance of engaging with carers and families
- The identification, development and implementation of strategies, process and resources that support carer inclusion as consistent with standards and legislation
- Increased provision of support and advice to carers.

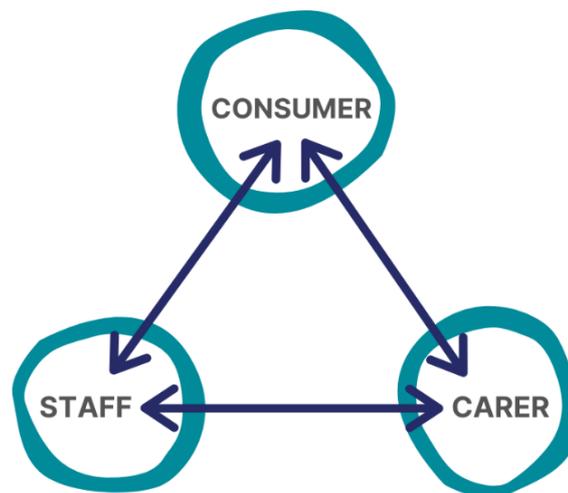


Figure 1 The Triangle of Care, adapted from Worthington, Rooney and Hannan, 2013

- One site observed an 8% satisfaction increase in their survey of ‘visitors and family’

Other pilot programs have included other demonstration projects in Victoria, South Australia and Tasmania. Such models have usually involved a mental health carers support agency working with health services to implement the Standards, such as the collaboration between Mental Health Carers Tasmania and headspace Hobart (Mental Health Carers Tasmania, 2018).

Carer Inclusion and Confidentiality

Confidentiality for the consumer is an issue that is often raised when advocates raise carer inclusion, and was raised multiple times in the Implementation reports of the *Practical Guide for Working with Carers of People with a Mental Illness* (Mental Health Carers Tasmania, 2018) (Lund & Stewart, 2018). However, denying carers access to information outright is likely to conflict with the Principles of the ACT *Mental Health Act 2015*, which contains the following:

“services provided to a person with a mental disorder or mental illness should— (...)

(ix) facilitate appropriate involvement of close relatives, close friends and carers in treatment, care or support decisions in partnership with medical professionals; and

(x) acknowledge the impact of mental disorder and mental illness on the close relatives, close friends and carers of people with a mental disorder or mental illness; and

(xi) recognise the experience and knowledge of close relatives, close friends and carers about a person’s mental disorder or mental illness; and

(xii) promote inclusive practices in treatment, care or support to engage families and carers in responding to a person’s mental disorder or mental illness”

These principles oblige mental health professionals to include carers in decisions and promote practices which include them in a person’s recovery. Under the Act, personal information can be disclosed with the patient’s consent. Given the stated benefit of carer involvement in recovery, professionals should seek consent for carer involvement on a regular, ongoing, basis. Where consent is refused, professionals should seek to understand the consumers refusal and work to identify when and how carers can be involved to encourage engagement between the consumer, carer and professional. These practices would facilitate appropriate and inclusive involvement of carers, as specified in the *Mental Health Act 2015*.

Currently, carers regularly report to Carers ACT that mental health professionals refuse to communicate with them at all, based on consumer confidentiality. This is often the case when professionals have not received adequate training to understand the complexities of balancing confidentiality and consumer rights (World Health Organisation, 2010). It is important to emphasise that even when professionals cannot discuss personal information with a person’s carer, they can still provide the carer with generalised information, advice, and support. For example, a professional could tell the carer what symptoms are common, which might indicate deterioration while at home and what treatments might be considered without providing information specific to the consumer. Mental health professionals also need to consider that without this information, there is a safety risk

to the consumer and carer. In Carers ACT consultations, professionals have indicated that they would like more training on consent and the information they can provide (Pretorius, 2020). Mental health services must provide clear guidance to their staff so it enables them to share tailored information about the illness with carers to support their care recipient's recovery, inclusive of situations where the consumer does not consent to the release of specific information.

Carers have said that they have felt overwhelmed by the amount of information available about the consumer's condition, and would prefer tailored, specific information about the illness, what symptoms to expect and what treatments they might recommend. Even where information specific to the person may not be shared due to confidentiality, carers indicated that general information on a diagnosis would help them continue their caring role and participate in recovery (Carers ACT, 2017).

CONCLUSION

Recovery-oriented mental health care has rapidly become the favoured model of care in mental health services in Australia. These models call on carers to participate in several ways to support the goals of consumers in recovery. Without increased education, support, and inclusion of carers, they experience increased stress and disempowerment. When advocates promote carer inclusion, consumer confidentiality may be cited as a barrier by mental health professionals. However with improved policy and practice around consent, these issues can be overcome.

Mental Health Carers Voice supports the use of the Triangle of Care and its adaptation in the *Practical Guide for Working with Carers of People with a Mental Illness* as a set of standards for improving engagement of carers in mental health services.

Recommendations

Mental Health Carers Voice recommends that:

1. Mental health services support carer involvement in recovery-oriented models of care, using the Triangle of Care model and the *Practical Guide for Working with Carers of People with a Mental Illness*.
2. Mental health services train staff in working with carers, and where possible, recruit carer consultants.
3. Mental health services provide clear guidance and training on communication with carers that is considerate of privacy concerns.
4. Mental health services create consent policies which require clinicians to seek consent from consumers on an ongoing basis, with a view to defining when and how carers can be involved.
5. Mental health services create carer information packs which provide general information for all carers.

6. Mental health services include carer engagement and support in their models of care.
7. Mental health services implement evidence-based tools such as 15-minute family interviews and the TOP 5 to engage carers in treatment and recovery (Pretorius, 2020).
8. All mental health services routinely collect the Carers Experience Survey, as recommended by the Productivity Commission Report on Mental Health (Productivity Commission, 2020).

Tools to Promote Carer Inclusion

Several tools and guides have been developed to promote carer engagement in services at both an individual and systemic level. The following are recommended by Mental Health Carers Voice:

- [The Practical Guide for Working with Carers of People with a Mental Illness](#)
 - [Free e-Learning modules](#) from Lived Experience Australia
- The Triangle of Care
 - [Toolkit, 2nd Edition](#) (Worthington, Rooney, & Hannan, 2013)
 - [Measuring Outcomes Information](#)
- The Mental Health Carer Experience Survey (AMHOCN, 2018)
 - [Technical Guide to Using the CES](#)
 - [Apply to use the CES in your organisation](#)
 - [Sample Survey](#)

In early 2020, MHCV completed an assessment of tools by clinicians which could be used to gather information from carers and families. In this, the 15-minute family interview (adapted from Family Nursing practice), TOP 5 and Carer Information Packs were identified as potentially useful for services to implement (Pretorius, 2020). We recommend that services review these tools and consider how they can adapt them for use.

- TOP 5 is a tool which helps the clinician ask a carer for the top 5 things they need to know about their care recipient to provide a safe environment.
 - [TOP 5 Resources from Mid North Coast Local Health District](#)
 - [TOP 5 Resources from NSW Clinical Excellence Commission](#)
- Carer Information Pack Examples
 - [Eastern Health \(Victoria\)](#)
 - [Somerset Partnership \(UK\)](#)
 - [East London NHS Foundation Trust \(UK\)](#)
 - [Support In Mind Scotland](#)

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