Vision Statement

People with lived experience have unique expertise that can be transformative for people who access services, their families, carers and for mental health services and systems.

To achieve a recovery-oriented system of mental health and social support, we need peer workers everywhere in that system. We need peer workers to provide peer support to consumers and carers. We need peer workers to participate in quality improvement, evaluation, and design of services. We need peer workers in policy and planning roles. We need peer workers in management positions and working as system leaders.
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Welcome to the Language and Concept Guide – Carer Peer Work

This language and concept guide for carer peer work addresses what a carer peer worker is, the particular characteristics of a carer peer worker and the unique contribution they make.

A number of specialist terms describe how the language and values of carer peer workers can transform aspects of mental health services. While many of these may be familiar to you, others may not. This guide has been produced to define the concepts and ideas that may require further explanation.

The National Consumer and Carer Forum states that because consumer and carers often have different sets of experiences ‘it is not appropriate to expect carer workers to be able to provide expert advice or assistance for consumers or for consumer workers to be able to provide expert advice or assistance for carers’.¹

This Language Guide is part of the suite of resources, Employer’s guide to implementing a peer workforce that includes: A case for your organisation that outlines the compelling rationale for including peer workers in your service. The Business Case will enable you to champion a peer workforce in your organisation by introducing how a diverse range of organisations have included peer work in their workforce mix and how this has improved their service delivery.

A Toolkit has also been developed as a practical guide to establishing a new peer workforce in your organisation or to assist you in expanding your existing one. The Toolkit covers progress from planning and recruiting through to supervising and evaluation. It discusses common challenges and how to manage them and also dispels common misperceptions about peer work and its value to your organisation.

Carer peer work and the language of recovery

A fundamental rationale for the introduction of a carer peer workforce is the importance of their contribution to recovery-oriented services.

The National Framework for Recovery-Oriented Mental Health Services explains the connection between recovery and lived experience.²

The lived experience and insights of people with mental health issues and their families are at the heart of recovery-oriented culture. The concept of recovery was conceived by, and for, people living with mental health issues to describe their own experiences and journeys and to affirm personal identity beyond the constraints of their diagnoses.

Recovery-oriented approaches recognise the value of this lived experience and bring it together with the expertise, knowledge and skills of mental health practitioners, many of whom have experienced mental illness in their own lives or in their close relationships.

Recovery approaches challenge traditional notions of professional power and expertise by helping to break down the conventional demarcation between consumers and staff. Within recovery paradigms all people are respected for the experience, expertise and strengths they contribute.

The language of the mental health peer workforce is underpinned by these recovery values that have grown out of the mental health lived experience movement. This language focuses on strengths and abilities, using terms that convey hope, rather than the language of deficits and hopelessness. It frames mental illness and mental illness as variations on human wellbeing and human differences. Many of the terms commonly used in mental health practice, however, are at odds with this approach.

The National Framework for Recovery-Oriented Mental Health Services advocates that ‘people-first’ language descriptors, consistent with the language of recovery, should be used wherever possible when speaking about people with a lived experience of mental illness or their family and supporters.³

Language can be used to help recovery by acknowledging the limitations of using a single set of terms. Therefore throughout the Employer’s guide to implementing a peer workforce, we use a number of terms interchangeably.

Following is a list of these most commonly used terms relating to mental health and peer work, and some alternative words with explanations for variations and preferences.

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³ C of A, A national framework: policy and theory, p. 5.
“As a peer worker our employers take us more seriously because we have a role, we are being paid, and our voice has to be heard.”

Sandra McDonald, Carer Consultant, Partners In Recovery, South Western Sydney
Definitions

Carer

In the mental health domain, ‘carer’ is commonly used to describe someone who provides unpaid care and support to a relative or friend who is experiencing a mental illness. However, some people don’t like to be referred to as a ‘carer’. As one mother explains:

My son is 26-years-old. To describe myself as his carer sounds inappropriate and patronising. It’s not a term he or I like. I am, and always will be, his mum ... and, as all mums are, his supporter.  

In the same way, some people prefer the word ‘family’, however when using the term family it is important to note:

For many people, the term ‘family’ may not refer to their family of birth, the family that raised them or a blood relative. Family is often their ‘family of choice’ rather than ‘family of origin’ ... We need to consult with the person about who they see as part of their family. Similarly, they should define who constitutes a carer or a friend.

Other preferred terms include ‘family supporter’, ‘recovery supporter’ and ‘recovery companion’. The term ‘natural support’ is preferred in growing numbers perhaps because it doesn’t disempower or stigmatise: ‘We all have natural supports; it is a normal, expected and desired part of most people’s lives.

In a similar way it is important to bear in mind that the word ‘carer’ may not translate across communities and cultures and you might need to find some other way of asking about these natural supports.

Carer peer worker

A person employed specifically to work from their experience of caring for or supporting a person with a lived experience of mental illness and recovery. Further a carer peer worker is required to use their lived experience purposefully to provide support and model hope for recovery, in addition to using their professional experience, training and array of abilities.

Many mental health workers have an experience of supporting a friend or family member who is experiencing mental illness, but this is not the same as being a carer peer worker. While both groups have an experience of supporting someone with mental illness, non-peer workers do not have to be open about, and purposefully use, this lived experience as a requirement of their role. In contrast, carer peer workers draw on their lived experience of supporting someone with a mental illness in the course of their work. Their job requires that their experience will be used in conversations, documentation, decision-making, and advocacy.

Health Workforce Australia (HWA) describes the importance of carer peer work:

Carer peer workers can provide support to families and carers, who may feel excluded when the person for whom they care is receiving mental health services. Again, the capacity to connect with someone who may have had a similar experience, and may offer understanding of the impact of the illness on significant others, is critical. Peer support can provide people with the chance to air their feelings – guilt, anger, worry and so on – in a safe environment, without fear of being regarded as disloyal or unsupportive. Often carer peer workers are involved in family education, which can increase the knowledge of families and carers about the illness or regarding coping strategies.

Carer peer worker roles

Carer peer workers can work across a number of areas in the mental health system, in public, community and private settings. Their most common role is carer peer support, directly supporting the family and carers of people experiencing mental illness by sharing their lived experience.

Carer peer workers can specialise in a particular role, service area or with particular population groups, for example an Aboriginal and Torres Strait Islander carer peer worker, a forensic mental health carer peer worker, dual disability / dual diagnosis carer peer worker and carer peer workers who primarily work with families, young people, young mothers and older persons. Such workers are sometimes known as carer peer worker specialists.

Carer peer workers also work across the mental health system in management, advocacy and representation; in policy and planning; as consultants and advisers; to promote health, educate and train; as supervisors, or to undertake quality, auditing and research.

For these reasons carer peer workers may be known by a variety of job titles. Some of these are listed in Mental Health Peer Work Literature Scan, including:

- Carer academic/researcher
- Carer advisor
- Carer advocate
- Carer assessor
- Carer companion
- Carer consultant
- Community support worker
- Carer coordinator
- Community Rehabilitation support worker
- Carer liaison officer
- Mental health outreach worker
- Carer policy officer
- Mental health rehabilitation support worker
- Carer provider
- Mental health support worker
- Carer representative
- Peer advocate
- Carer support worker
- Peer mentor
- Carer team leader
- Peer respite worker
- Carer worker
- Peer specialist
- Peer support worker
- Recovery advisor
- Carer educator.


Carer peer work values

Carer peer workers, like their consumer peer worker counterparts, are guided by a set of values in undertaking their work. These values include:

• Mutuality and reciprocity
• Responsibility
• Self-determination
• Empowerment
• Participation
• Equity
• Recovery and hope.

Many of these values are picked up in the definition of a carer peer worker offered by the National Consumer and Carer Peer Work Qualification Development Project Reference Group:

A carer peer worker draws upon their lived experience to encourage an environment of sharing and support founded on the principles of respect, shared responsibility and mutual agreement of what is helpful to identify and meet the needs of each family/carer.¹⁰

The resources developed for the Certificate IV in Mental Health Peer Work suggested six characteristics of caring relationships which may be common in the carer and carer peer worker relationship:

• Hope-inspiring relationships
• Empowering relationships
• Mutually supportive relationships
• Peer relationships
• Spiritual relationships
• Having someone to stand alongside you.¹¹

Family and carer peer workers generally work within a framework of family-centred practice. Children of parents with a mental illness (COPMI) explains that there are four core elements of family-centred practice:

• The centrality of the family as the unit of attention
• An emphasis on maximising families’ options and choices
• A strengths, rather than a deficits, perspective
• Cultural and spiritual sensitivity.

Family and carer peer workers practising within a strengths-based approach seek to support families as a whole unit (however they define themselves) to strengthen their collective and individual resources.¹²

Consumer

This refers to a person who has had a personal experience of mental illness and who has used mental health services. Consumers often advocate for mental health service reform based on their experiences. Official Australian legal and policy documents generally use the term ‘consumer’, but not all people choose to use this term in relation to themselves. There is a growing preference for the simple term of ‘person’ or ‘person with lived experience of mental illness’ instead of consumer.

There are reasons why this is increasingly being used:

One of the beauties of the term ‘lived experience’ is that it talks about a far wider array of experiences than the term ‘consumer’. ‘Consumer’ implies that we must have consumed mental health services. ‘Lived experience’ is also inclusive of those people who share similar experiences of difference and distress but who have not been consumers/survivors/guests of the mental health system.¹³

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¹¹ MHCC, Working with and supporting carers, pp. 11–16.
When people offer each other encouragement, empathy, hope, consideration, respect and empowerment from the vantage point of experiential understanding. The ‘been there, done that …’ connection creates a unique understanding and eliminates the power and authority typically associated with helper, support or clinical roles.

Other common alternatives to consumer include a person with lived expertise or experts by experience or lived experience practitioner.

**Consumer peer worker**

A person specifically employed to work from their personal lived experience of mental illness and recovery. Further a consumer peer worker is required to use their lived experience purposefully to provide support and model hope for recovery, in addition to using their professional experience, training and array of abilities.

**Lived experience**

‘Lived Experience’ can refer to a variety of experiences including a personal lived experience of mental illness and/or an experience of supporting or caring for someone with a personal experience of mental illness. It may also have the added layer of gender, ethnicity or age that can influence how someone might interact with the mental health system.

**Lived experience practitioner**

See ‘Peer Worker’

**Mental illness, mental health issues, mental ill health**

The terms ‘mental health issues’, ‘challenges’, ‘mental ill-health’ and ‘emotional distress’ are sometimes used in place of, and at times alongside, the term ‘mental illness’.

**Peer support**

People with a lived experience of mental illness support each other in their recovery journey. Support may be formal or informal, voluntary or paid. It may be stand-alone support or part of an initiative, program, project or service which is run either by peers themselves or by professional service providers.

A carer peer peer support role is one of the major jobs for a professional carer peer worker. Peer support is:

> When people offer each other encouragement, empathy, hope, consideration, respect and empowerment from the vantage point of experiential understanding. The ‘been there, done that …’ connection creates a unique understanding and eliminates the power and authority typically associated with helper roles.

Most of the experience and research in carer peer work to date is in relation to their peer support role. However organisations are still encouraged to think broadly about the types of roles that, by bringing in lived experience of carers, could provide enhanced value to the delivery of services.

15 Commonwealth of Australia, A national framework: policy and theory, p. 5.
16 Commonwealth of Australia, A national framework: policy and theory, p. 34.
18 Commonwealth of Australia, A national framework: policy and theory, p. 34.
Peer worker

A person employed to work specifically from either their personal lived experience of mental illness and recovery, or their lived experience of supporting family or friends with mental illness. Shared lived experience brings with it a unique understanding of each other, an equality of status and a relationship of equals. The term ‘peer worker’ is used interchangeably with the term ‘lived experience practitioner’ and a range of job titles may be used depending on the specific nature of the role. (See above, Carer peer worker roles, for some examples.)

In line with this definition, for the purposes of this peer work guide, ‘peer worker’ will refer to:

- people employed to work specifically from their personal lived experience of mental illness and recovery along with their professional experience, training and abilities (consumer peer workers)
- people employed to work specifically from their lived experience of supporting family or friends with mental illness, along with their professional experience, training and abilities (carer peer workers).

Recovery

This 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 illness. This period is also known as personal recovery.18

Recovery-Oriented Practice

This 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.19

Recovery-Oriented Service Delivery

This refers to the delivery of evidence-based treatment and support that centres on individual needs and aspirations.20 Evidence-informed treatment, therapy, rehabilitation and psychosocial support aim to achieve the best outcomes for people’s mental health, physical health and wellbeing.21

The National Framework for Recovery-Oriented Mental Health Services is a detailed guide that outlines what recovery-oriented service delivery looks like. It defines five practice domains:

1. Promoting a culture and language of hope and optimism
2. Person first and holistic
3. Supporting personal recovery
4. Organisational commitment and workforce development
5. Action on social inclusion and the social determinants of health, mental health and wellbeing.

Domain 2 includes the capability of being responsive to families, carers and support people and viewing them as partners. This means that services must address the needs of these people for information, education, guidance and support. The capability asks that mental health practitioners and providers ‘understand and empathise with the journeys of recovery, healing, wellbeing, growth and learning that families are undertaking’. One way to meet the requirements of this capability is by increasing the opportunities for carer peer workers in your organisation.22

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18 Commonwealth of Australia, A national framework: policy and theory, p. 34.
19 Commonwealth of Australia, A national framework: policy and theory, p. 5.
## Summary of Terms

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<tr>
<th>Term</th>
<th>Definition</th>
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<tr>
<td><strong>Carer peer worker</strong></td>
<td>A person employed specifically to work from their experience of caring for or supporting a person with a lived experience of mental illness, as well as their professional experience, training and other abilities.</td>
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<td><strong>Clinical recovery</strong></td>
<td>A reduction or cessation of symptoms and ‘restoring social functioning’ This term is primarily used by clinicians. See also personal recovery.</td>
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<tr>
<td><strong>Consumer peer worker</strong></td>
<td>A person employed to work from their personal lived experience of mental illness and recovery, as well as their professional experience, training and other abilities.</td>
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<tr>
<td><strong>Lived experience</strong></td>
<td>The experience people have of their own or others’ mental illness, emotional distress or mental illness, and of living with, and recovering from, the impacts and consequences of their own or others’ emotional distress or mental illness.</td>
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<tr>
<td><strong>Lived experience practitioner</strong></td>
<td>See peer worker.</td>
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| **Peer worker**             | A person employed to work specifically from their personal lived experience of mental illness and recovery, or from their lived experience of supporting family or friends with mental illness. The term ‘peer worker’ is used interchangeably with the term ‘lived experience practitioner’.
| **Recovery**                | The ability to create and live a meaningful and contributing life in a community of choice with or without the presence of mental illness. See also clinical recovery. |
| **Recovery-oriented practice** | Sets of capabilities that support people to recognise and own their recovery and wellbeing and to define their goals, wishes and aspirations. |
| **Recovery-oriented service delivery** | Evidence-informed treatment, therapy, rehabilitation and psychosocial support that incorporates recovery-oriented practice. |
## Language alternatives

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<td>Mental illness</td>
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<td>Mental ill-health</td>
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<td>Emotional distress</td>
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References


COPMI – See Children of parents with a mental illness

CWC Framework – See NSW Mental Health Consumer Workers Committee


HWA – See Health Workforce Australia.


NSW Mental Health Consumer Workers Committee & BEING (formerly NSW CAG), A Framework for the NSW Public Mental Health Workforce, Sydney, 2013.


Mental Health Coordinating Council, Working with and supporting carers: Resource Book, Sydney,

MHCC – See Mental Health Coordinating Council.


NMHCCF – See National Mental Health Consumer and Care Forum.


WA Australia Mental Health Commission – See Government of Western Australia Mental Health Commission.
This resource in the Employer’s guide to implementing a peer workforce is supported by the Mental Health Commission of New South Wales.