



Developing a Peer Workforce for Eating Disorders

The Peer Work Approach



Part B

Using this Guide

The Guide is designed to facilitate access to the available evidence and resources on peer work that are most relevant to eating disorder service provision.

The intended audiences for the Guide are:

- Health service executives, planners and decision makers
- Human resource professionals
- Health professionals with responsibility for implementation, supervision and working as part of an integrated team
- People with lived experience who are considering becoming peer workers

The Guide is presented in three parts:

Part A: Exploring the Evidence for Peer Work in Eating Disorder Settings

Part A provides a brief outline of the evidence reviewed in the development of this Guide

Part B: The Peer Work Approach



This document

Part B provides an introduction to peer work practices which can enhance outcomes for people with eating disorders.

Part C: Organisation Matters

The four guides in Part C explore some of the organisational support strategies that have been found to assist in the development of safe and effective peer work initiatives. The documents in Part C may assist in the planning, implementation and evaluation of peer work initiatives. It may also provide useful content for training for peer workers and for clinicians.

C1. Codesign for Change

C2. Robust Recruitment

C3. Supporting Practice – Supervision and Training

C4. Introductory Training Resource

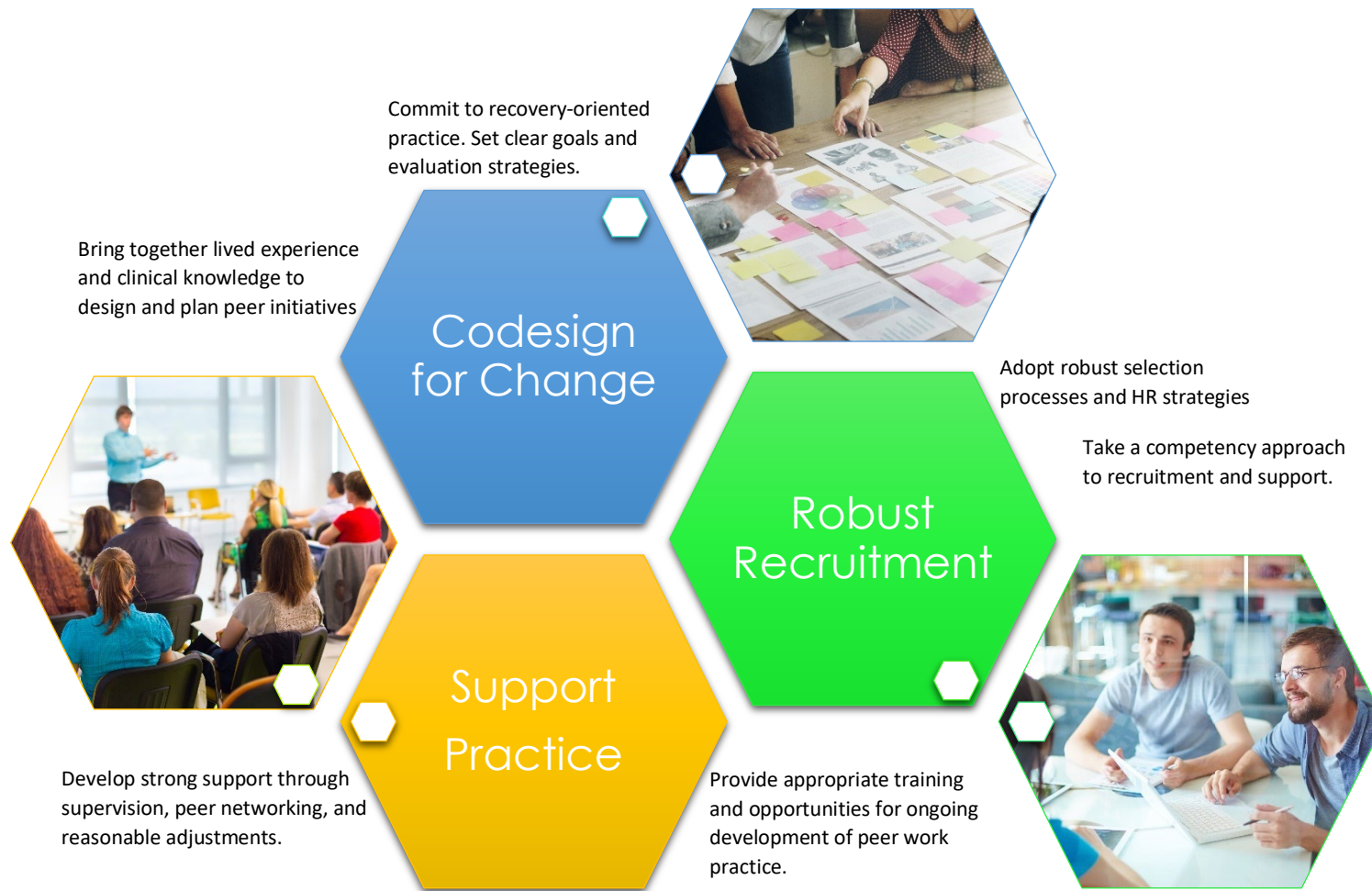


Figure 1: Organisational Steps Towards Safe Effective Peer Work

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Symbols used in this resource:



Reference or useful further reading



Online resource



Key information



Opportunity to explore the topic further

Language

This resource draws on content from many different published sources as well as input from people with lived experience of eating disorders and their families, clinicians and other supporters. The words that these sources use to describe people vary, including familiar terms such as consumer, carer, service user, and client. These are all terms that appear in relevant practice standards and guidelines. The terms used in this resource reflects this diversity. We have not tried to impose a best-practice standard of language.

Language is very important to the way that people think and feel about lived experience. Wherever possible we have used the terms 'person' and 'people' in preference to terms such as service users, clients or patients.

Where we have chosen the terms for this resource, we have used the following:

Lived Experience – someone with a personal experience of an eating disorder.

Peer – people who have a similar experience of mental illness and who share some areas of interest. In this Guide, the term 'peer' refers to someone with lived experience of an eating disorder, or a family member or other supporter who has experience supporting someone with an eating disorder.

Peer Worker – someone with lived experience or someone with experience as a supporter who is employed, in a paid or voluntary capacity, and trained to draw on that experience to help others to recover (Slade et al., 2014).

Recovery – a process of gaining personal control and working towards a meaningful life that is not dominated by the symptoms of an eating disorder. Recovery is something that everyone experiences in their own way after challenging life events, including people who have experienced illness, their family members and other supporters.

Supporter – someone who has experience providing practical and emotional support to a person with an eating disorder on an unpaid basis, for example as a family member, partner or friend.

What do we mean by eating disorders?

Eating disorders are a group of serious and complex bio-psychosocial disorders that range in severity from moderately-severe through to critical and life threatening. These disorders are characterised by disturbances of eating behaviours and consequent malnutrition; psychological distress and a core psychopathology centred on food, eating and body image concerns. The group

'Feeding and Eating Disorders', as defined in the DSM-5, includes: anorexia nervosa, avoidant/restrictive food intake disorder (ARFID), binge eating disorder, bulimia nervosa, elimination disorder, other specified feeding and eating disorders (OSFED), and pica and rumination disorder. The term 'eating disorder' is used in this guide to collectively refer to these conditions. All diagnoses are associated with significant physical health complications and nutritional health issues (Hay, Chin et al., 2014).

Defining Peer Work



Peer workers are people who draw on their lived experience and knowledge of recovery from an eating disorder to help others achieve improved recovery outcomes.

Peer work is a non-clinical, collaborative approach in which people with lived experience and people who have supported others with an eating disorder use their experience to help others work towards their own recovery. Peer workers are employed in traditional health service settings, in community service and education settings, and in peer led community initiatives.

Peer workers may:

- ▶ Work directly with others with lived experience, e.g. to provide support, information, education, coaching, counselling
- ▶ Work with health professionals and service providers to ensure that the services delivered are person centred and recovery oriented, e.g. through clinician education; service and practice design; research and evaluation.

These roles are not mutually exclusive. Peer workers may work directly with their peers and also contribute to service improvement.

The focus of this guide is on peer workers who are employed in roles that require them to intentionally draw on their own experience of eating disorders as an essential part of the work (MHCC, 2014). Characteristics of formal peer work include:

- ▶ Formal employment (paid or voluntary) in a clearly defined job role
- ▶ Training, supervision and support are provided as an integral part of employment
- ▶ Role purpose is to engage in relationships with peers and health professionals to support them to achieve improved recovery outcomes
- ▶ Lived experience of an eating disorder or of supporting someone with an eating disorder is an essential qualification for the role; other qualifications are required relevant to the specific job role



Peer work supports creating new ways of engaging with life through supportive relationships.

Peer workers help to provide a safe, supportive environment in which people are able to openly share and reflect on their experience, creating new ways of engaging with and understanding life.

The Peer Support Charter

“Peer support is intrinsic to mental health and total wellbeing. Why? Because it provides an unmatched, unlimited pathway to help, in a safe environment, where people’s shared lived experiences are heard, respected, honoured and understood”.



For more information on the Peer Support Charter visit: www.peersupportvic.org



"A system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful. When people find affiliation with others they feel are 'like' them, they feel a connection... people are able to 'be' with each other without the constraints of traditional (expert/patient) relationships."
(Mead, Hilton & Curtis, 2001)

The Peer Workforce: Who can be a peer worker?



Our peers are people who have shared similar experiences, learned from their experience and who are able to meet us as equals in the middle of life's challenges.

Peer services are based on the belief that people who have lived through life changing experiences, such as an eating disorder, are the ones best placed to relate to others dealing with similar issues.

A peer is someone who is equal to another in status and who shares some of the same experiences and interests. A peer is often someone at a similar stage in life, dealing with the same sort of daily situations. In mental health, a peer is someone who has experience of the same sort of mental illness and has experience of personal recovery. A peer in this context will have progressed further through their recovery journey than the person they support. Families and other supporters also need access to people who they can easily relate to and with whom they feel safe to share their experiences.

Peer workers include:

- People who have personal experience of an eating disorder and of working through recovery
- Family members and others who have experience of supporting someone with an eating disorder. Family members and supporters will also have worked through their own personal recovery from the stressful and sometimes traumatic experiences of providing care.

Service User Peers

Some health services engage people who have used the service (e.g. the hospital) as peer support workers for other users of the service. This approach to peer work emphasises the shared experience of place and systems rather than a shared experience of a specific illness and type of treatment.

This is not the optimal approach for people with eating disorders. The hope inspired by peer workers is based on the potential for recovery from the eating disorder and this can only really be modelled by someone who has recovered, or supported someone to recover, from an eating disorder.

Peer workers with a shared experience as service users need to keep in mind that the person with an eating disorder is not receiving the same treatment or experiencing the environment in the same way as others. Regular daily activities, such as meal times, may have a very different impact on someone with a severe eating disorder. The service user peer is able to offer respectful listening and emotional support to help until the person can be connected with an eating disorder peer worker.



The Peer Work Approach: What makes peer work different?



The peer worker helps people with eating disorders, families and clinicians to think differently and to galvanise positive change.

1. A different goal – discovering life through personal recovery

The focus of peer work is on personal recovery; a focus on the person rather than the illness.

Personal recovery refers to the work that the person does, taking responsibility for the direction of their life and actively bringing about change (Glover, 2012). The work of personal recovery helps the person to move towards a sense of self as the active agent in their own life, gradually taking responsibility and control over life (Andresen, Oades and Caputi, 2011; Glover, 2012).

People with eating disorders understand recovery as a process of regaining a satisfactory life that is no longer dominated by their eating disorder (Butterfly Foundation, 2016).

“Recovery is something that we do for ourselves, not something that is done to us. The real work – the heavy lifting of life – is ours. Recovery is a commitment to self” (NEDC Stories from Experience, 2015). “Everyone seems to agree that personal recovery is just that – personal. Recovery isn’t the same thing for everyone. The metaphor of recovery being a journey is a good one because we all start from different places, travel different roads through different experiences and end up at different destinations. There is no particular standard that has to be achieved. Recovery in your life is whatever you are looking for and whatever you are prepared to work towards. Recovery in someone else’s life may look different”.

The eating disorder is experienced in the context of daily life and people need to understand their recovery in this context, as an integrated part of life and not as something separate (Cook and Morgan, 2016). Recovery helps people to make sense out of what has happened to them and how they feel. The process brings together the different threads of experience and daily life into a meaningful pattern. This is a highly individual experience.

“Recovery means breaking free of illness to be myself and finding and liking who I am – not just my body but who I really am as a person.” (Butterfly Foundation, 2016)

This approach to recovery links to **Competency Group 1: Knowledge and lived experience of recovery from an eating disorder** in Part C2 of this Guide.

2. Unique tools – using lived experience to facilitate change



Peer workers draw on their personal experience to help others navigate their own recovery.

“Consumers have developed ways of knowing and understanding their experiences that constitutes a unique discipline in the field of mental health” (Roper, Grey and Cadogan, 2018).

Lived experience is knowledge that cannot be acquired in anyway other than through direct experience. This is the personal knowledge of how illness and treatments are experienced and understood; how illness impacts on identity, feelings, relationships and daily life; and knowledge of the practical processes of recovery.

The skill required for peer work is the ability to draw on this knowledge to assist and support others through their own process of recovery. This is not a skill that everyone with lived experience will naturally develop. It involves the development of reflective abilities and self-awareness, purposeful sharing, awareness and respect for diversity in experience, and the ability to work collaboratively with others. Peer workers have three unique and valuable tools to work with:

▶ **Knowledge**

Through their lived experience, peers have a frame of reference to understand and empathise with others' experiences (Mead and MacNeil, 2006; Jacobsen, Trojanowski and Dewa, 2012). Knowledge from lived experience provides insights into illness, treatment and recovery that can assist health professionals and families as well as people with eating disorders.

▶ **Disclosure**

Drawing on personal experience of mental illness is the defining characteristic of peer work. By purposefully using their own experience, peer workers are able to engage others, build trust, and encourage others to disclose their experience and develop their own understanding of what has happened to them (Slade et al., 2014). The language that peer workers use is the ordinary everyday language which is best suited to sharing feelings and relating to daily experiences (Proudfoot, Jayawant, et al., 2012). Disclosure adds to the credibility of what the peer worker has to say.

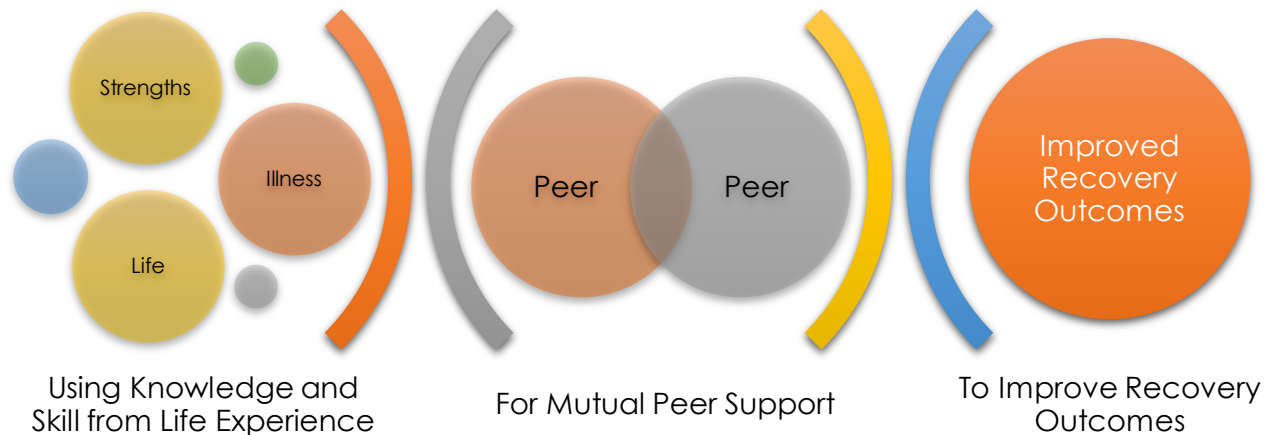
► **Role modelling**

Peer workers provide a tangible example of recovery. They model some of the daily behaviours that can contribute to achieving recovery goals (Jacobsen, Trojanowski and Dewa, 2012).

The knowledge of lived experience is practical, contextualised for daily living, and credible (Mead and MacNeil, 2006; Proudfoot, Jayawant, et al., 2012). Peer relationships provide an effective way to transfer knowledge, build skills, and inspire a sense of agency and hope. Hope is the foundation of personal recovery. Peer workers are able to demonstrate through their words and actions that recovery is real, inspiring hope in others for their own recovery.

Using these unique tools links to **Competency Group 2: Purposefully apply lived experience to promote and support recovery** in Part C2 of this Guide.

{ “The best way to learn about recovery from an eating disorder is from people who have experienced recovery.”
(Cook and Morgan, 2016) }





For a discussion of the change mechanisms involved in peer to peer work, see: Gillard, S., Gibson, S., Holley, J., & Lucock, M. (2015). Developing a change model for peer worker interventions in mental health services: A qualitative research study. *Epidemiology and Psychiatric Sciences*, 24(5), 435-445. doi:10.1017/S2045796014000407

Lived Experience of Recovery

To do this work, peer workers need to have made some sense of their own mental health challenges and have achieved some emotional distance from their experience. There is no perfect state of 'being recovered'. Lived experience of recovery means that the person:

- Has engaged in the recovery process of motivated change
- Is currently able to manage their own wellbeing
- Can reflect on what they have been through and learn from their experience
- Can stand back from their experience to consider the wide range of different experiences that other people may have
- Identify when their own wellbeing is at risk and ask for help when they need it.

Family members and supporters also experience recovery, firstly by observing the person they support work through the process, and secondly by making their own progress towards recovery from the stress of caring for someone with an eating disorder.

Recovery is something that everyone needs to do after difficult experiences in life.



National Mental Health Commission (NMHC) (2018). Sit beside me, not above me: Supporting safe and effective engagement and participation of people with lived experience. Australian Government, Canberra.

<https://mentalhealthcommission.gov.au/media/253244/Sit%20beside%20me,%20not%20above%20me%20-%20Supporting%20safe%20and%20effective%20engagement%20a....pdf>

A Skills Based Approach

“Lived experience is only one skill or attribute which a person may need to perform a particular role or function, and the full range of skills required will change according to the role. There is a difference between experience and expertise and it is recognised that as the roles of people with lived experience move ‘higher’ or expand in scope, so does the need for different levels of expertise. For example, a person may have skills as a peer worker engaged in supporting individuals in their recovery journey but this in itself does not equip them to participate on national, state or territory mental health commissions, boards or broader policy advisory committees. Similarly, people working at systemic levels may not have worked on the frontline and may not necessarily have the skills to provide effective and meaningful peer support at an individual or group level. Each role has different objectives and requires a different range of skills”. (NMHC, 2018)



3. Building trusting relationships



Peer workers provide a safe, supportive environment in which people are able to openly share and reflect on their experience.

People with eating disorders often feel disconnected from those around them and from the activities that used to be important in their life. Improving a sense of connection with others is one of the most commonly identified needs to support personal recovery (e.g. Hay and Cho, 2013; Proudfoot, Jayawant et al., 2012). Self-acceptance is another common need (Bjork and Ahlstrom, 2008). People with eating disorders need to be able to connect with themselves and their emotions as well as build relationships with others.

“People make sense of their experience of eating disorders and find acceptance through their connectedness with others” (Cook and Morgan, 2016).

“It's easy to forget who you are in treatment. If people can't relate to who you are as a whole person, what happens to your identity” (Butterfly Foundation, 2016)

Stigma is a factor in this sense of disconnection with self and others. People with eating disorders talk about their sense of 'self-loathing' (Butterfly Foundation, 2016) and expect that others would reject them if they knew what was going on in their minds. Stigma occurs when someone is perceived as having a negative attribute that makes them seem of less value as a person. In practice, stigmatising attitudes contribute to prejudice and discrimination.

Experiencing stigma and discrimination contributes to feelings of shame, helplessness, fear, worthlessness, distress and self-doubt. People who experience stigma, or are afraid of community attitudes to their mental illness, are less likely to seek help or disclose their mental illness, leading to social isolation and lack of essential treatment. Providing effective role models through peer work positions can be helpful in improving a person's capacity to respond to stigma and discrimination.

“For most people a sense of safety happens in the context of mutually responsible, trusting relationships. It happens when we don't judge or make assumptions about each other. It happens when someone trusts/believes in us and it happens when we are honest with each other and own our own discomfort”. (Mead and MacNeil, 2006)

People with eating disorders often do not readily trust their treatment team. Working with someone who has recovered and who they trust can be the greatest agent for change. Peer work may be the source of motivation that helps to make treatment more effective. Similarly, families and carers may not be comfortable with treatment strategies. These often challenge their understanding of good parenting. A carer peer worker can help them to understand the treatment and their role in the treatment, personalising this to the family's everyday life.

Peer work starts by building an equal relationship based on genuine concern, empathy, clear communication, companionship and shared information. There is no pressure in this relationship to achieve goals that have been set by others (Jacobsen, Trojanowski and Dewa, 2012). Peer work relationships help people to feel safe and understood, connected in a relationship of mutual responsibility. This relationship helps to protect the person from the inevitable stresses involved in treatment and change, and prompts the development of helpful behaviours (Proudfoot, Jayawant, et al., 2012).

The peer worker reduces the impact of stigma by respectfully engaging the other person, and by role modelling a position of respect within the clinical team. Through this relationship, people are able to move towards hope and motivation and a greater sense of personal agency in their own recovery (Repper, 2013).

The ability to build peer relationships links to **Competency Group 3: Establish relationships of mutual trust and respect** in Part C2 of this Guide.



4. A collaborative approach – working through mutual help



Peer work requires a commitment from all participants to listen and learn from each other.

Peer work requires a commitment from all participants to listen and learn from each other. Health outcomes are coproduced in an equal and reciprocal relationship between professionals, people using services, their families, and peer workers (based on New Economic Foundation's definition of co-production, 2011).

Each person – service user, peer worker, family and clinician – brings strengths and knowledge to the relationship, and each person has an opportunity to express their ideas and take responsibility for the outcomes of the relationship. This is a mutual process; a dynamic conversation in which both parties give and receive, learn and change.

By definition, peers are equals. The person receiving the service chooses to participate rather than having to participate as a requirement of treatment. This act of choice is what helps to make the process meaningful. If the person feels that they must use the service, the equality of relationship is threatened.

“Recovery is a personal choice. The most basic value of peer support is that people freely choose to give or receive support. Being coerced, forced or pressured is against the nature of genuine peer support. The voluntary nature of peer support makes it easier to build trust and connections with another.” (SAMHSA, National Practice Guidelines for Peer Supporters)

“Mutual help in peer support... means sharing our vulnerabilities and our strengths and finding value in each other's help. In peer relationships it is important to remember that it is not our task to assess or evaluate each other but rather to say what we see (our perspective), what we feel, and what we need to build connection”. (Mead and MacNeil, 2006)

The peer worker's role is defined by their connections and ability to work with others (Jacobsen, Trojanowski and Dewa, 2012). For some peer work roles, the peer worker is an equal partner in the clinical team.

The vision of equality and co-production in mental health care is inspiring but not always the way that people experience their involvement with health services. A co-production approach involving all levels in the organisation is critical to the success of lived experience roles with strategies in place to ensure that lived experience workers have equal voice in the team.

The ability to work collaboratively links to **Competency Group 4: Work collaboratively to enhance recovery outcomes** in Part C2 of this Guide.

Many Different Roles: What do peer workers do?

Peer to Peer Roles

Some peer work roles focus on the relationship between the peer worker and the person using the service. The activities of these peer support roles vary between individuals and organisations however, they typically include one or more of the following:

- ▶ Providing social, emotional and practical support to individuals face to face or by telephone or online support
- ▶ Facilitating and leading peer support group programs
- ▶ Informing, educating or training individuals or groups
- ▶ Individual mentoring or coaching
- ▶ Organisation and administration of peer work programs
- ▶ Supervision, support or leadership of peer workers and peer work teams.

(Jacobsen, Trojanowski and Dewa, 2012; Bell, Panther and Pollock, 2014)



Lived Experience Roles

Some peer work roles focus on the relationship between the peer worker and health professionals, governance or service development groups, or family members. The focus of the work is still to improve the experience of service and recovery outcomes for people with eating disorders but the relationships may be indirect or team focussed rather than focussed solely on the person with an eating disorder. The activities of these lived experience roles may include:

- ▶ Educating health professionals
- ▶ Health promotion and awareness raising (e.g. community outreach)
- ▶ Working as a member of the clinical team or as a lived experience consultant to clinical teams
- ▶ Co-delivery of group therapy, education or support with a health professional
- ▶ Co-design of programs, information and other resources
- ▶ Investigation and information gathering; evaluation or research

Including peer consultants in the treatment team can help to bridge the sense of disconnection that people with eating disorders and their clinicians often feel.

Facilitating communication and relationship building between services and service users helps to integrate clinical treatment and personal recovery experiences. Peer worker knowledge can improve the design of programs and practices and increase their effectiveness (Valenstein, Pfeiffer, Brandfon et al., 2016).

Mentoring and Lived Experience Consultant Roles

Peer to peer roles and lived experience consulting roles draw on different skills sets and are driven by different personal and organisational motivation. Workers experience each type of role differently and may require access to different types of training, including potentially clinical training.

“The premise of being a lived experience worker is different to that of a peer mentor. Mentoring isn’t professional; it is all about personal experience, relationship and mutual support. Lived experience work is closer to a clinical role as you have to conform to the agenda of the organisation. Peer work can push you out of your comfort zone and outside the sense of building a real relationship. Power issues start to emerge. On the whole, peer mentoring is more rewarding and satisfying than peer work.

Lived experience work is how I use my experience in a structured environment to help others. Mentoring is less about my story and more about how I relate to the other person by being myself. Mentors do not need better job descriptions. The role develops in the relationship between mentor and mentee. Every relationship is different. The more you mandate this from an organisational perspective the more you disrupt the development of the relationship”. (NEDC Interviewee, 2018)

The Connection Between Peer Work and Mentoring

Mentoring is a voluntary relationship in which a more experienced person helps to guide someone with less experience. Mentoring is a partnership that requires time so that both people can learn about one another and build a relationship of trust in which difficult issues can be raised.

Mentors:

- **M**anage and develop the relationship
- **E**ncourage the other person
- **N**urture and contribute to the other person's growth
- **T**each relevant skills
- **O**ffer mutual respect
- **R**espond to the other person's needs

(based on an acronym by Clutterbuck, 2004)

Being a Peer Worker – A Personal Reflection

To be a Peer Worker is to give back what you have learnt from lived experience to assist those along their personal and unique journey. To be truly recognised that your own experiences are worthy, valid and increasingly becoming an important role in the recovery of others. My experience has been of walking beside a person as a support and source of hope to reassure that what they are experiencing through the illness, there is another side in recovery. Peer work is modelling, sharing and providing optimism for the future ahead.

Negotiating challenges and how I deal with them comes down to a personal self-care and establishing boundaries that have been strengthened by undertaking Peer Work. Peer Work has given me the confidence and ability to navigate from uncomfortable situations and to maintain personal wellbeing in a workplace that is supportive and understanding of the background I have previously come from, allowing myself to express and be comfortable to continue and contribute to my own growth as well as give back and be confident in my identity.

The work I have undertaken as a Peer Worker has been valuable to my life experiences and continued journey of recovery and involvement in a part of my life that essentially been most of experience so far. Challenges have arisen whilst undertaking work that is personal and on an emotional level and it is important to have strategies in place to deal with issues. I have navigated difficult situations by stating what I am comfortable and not comfortable with whilst undertaking the role and also having support in the workplace environment to be able to debrief and assess overall status with the clinical team. Having continued support as a Peer Worker has become an essential part of the role.

A large part of overcoming and preventing difficulties if they do come up is making sure I personally look after myself by engaging in my own selfcare and by also engaging in activities away from Eating Disorders and Issues as a part of a healthy balance, which was a part of my own recovery process. A degree of flexibility has also been helpful in the role to account for unseen circumstances that may have come up that have directly affected as a Peer Worker to allow to process.

Being a Peer Worker is rewarding and offers an element that has not been typical in treatment before. It benefits both the person with the Eating Disorder and contributes largely to the ongoing recovery of the Peer Worker. By having strategies in place to deal with issues that may arise in the role allows a Peer Worker to feel supported in the work that is undertaken.

Lexi Crouch

Clinical Roles and Lived Experience



Anyone can develop an eating disorder. People who work as health professionals are as likely to have lived experience of an eating disorder as other people in the community. People who have navigated their own recovery often want to help others; some choose to become health professionals. Studies indicate that around one third of clinicians specialising in eating disorders have previously experienced an eating disorder (Johnston, Smethurst and Gowers, 2005).

Lived experience can enrich the clinical knowledge of health professionals and enable them to understand what the people they work with are going through. For some people, knowing that their clinician is speaking from experience as well as from theoretical knowledge can help them to feel more confident about the care they are receiving.

Peer work roles must be carried out within the framework of peer work principles and unique approaches (Swarbrick, 2013). A peer worker must disclose their lived experience as part of their work. Some professional standards limit self-disclosure and this limits the roles that may be jointly identified as both peer work and clinical.

The focus of this Guide is on peer work roles as an approach that is non-clinical but complimentary to clinical treatment and treatment outcomes.

Matching Peer Work to Recovery Needs

Peer work for people with eating disorders may be most effective when the peer worker and the person or group they are supporting are matched for similar experience of illness and similar age and stage of life (Butterfly Foundation, 2016; Faulkner and Kalathil). Matching peer workers and the people they support benefits both people (Perez, Kroon Van Diest and Cutts, 2014).

“Our program uses a matching process for mentors and mentees. Both mentors and mentees complete a detailed form about themselves which provides the initial information for matching. Their priorities are identified in terms of how important it is for them to work with someone of the same gender, in the same location, or with a similar eating disorder history. We also ask broader questions about what inspires them, what they are interested in, what has been beneficial to them so far. Sometimes, supervisors need to clarify these priorities when there are no mentors who would be an exact match. The information is updated as life changes. Self is not static. The matching process has the advantage that supervisors get to know both the mentor and the mentee very well”. (NEDC Interviewee, Eating Disorders Victoria Peer Mentor Program)

Matching Peer Work to Stage of Recovery

Peer workers are ideally engaged early in the journey through treatment. People with eating disorders and their supporters may need information, motivation and more intensive support early in treatment. Engaging the carer peer worker early in the journey through treatment enables the family or carer to play an active role as an integral member of the treatment team.

Peer support is most likely to be helpful early in the recovery journey when feelings of shame and disconnection are strongest. However, there is a point in recovery where the person needs to turn away from the factors that keep them centred in an eating disorder identity and start to become more involved in life. As people re-connect with relationships and activities, peer support may be less helpful. For example, internet peer groups have been shown to be helpful in the early stages of recovery and of less value in later stages (Keski-Rahkonen and Tozzi, 2005).

Peer support may be provided at different intensities depending on where the person receiving the service is in their journey, e.g.

- ▶ Intensive 24/7 access to support
- ▶ Outreach and in-home support
- ▶ Intensive educational and/or support groups
- ▶ Individual mentoring sessions
- ▶ Casual 'catch up' sessions.



Peer Support for Families and Carers

“It is best practice for all parents and families to be given the option and support to play a central role in the treatment and recovery of their family member with an eating disorder. Such collaborative approaches result in better long-term outcomes for our loved ones, more resilient families and less impact on our health system. Eating disorders peer support is critical for families and carers and should be accessed as soon as possible in the journey of caring for someone with an eating disorder. Peer support can be in-person or online” (Eating Disorder Families Australia).

Supporting someone with an eating disorder is a daily challenge. Family members are critical members of the treatment team for young people and may continue to have this role for adults. In some treatment approaches, like Family Based Treatment (FBT), parents or other carers are the active agents in treatment, taking an integral role in delivering the treatment in the home environment, supported by supervision from the treatment team. The onus is on the family or other supporters to learn very quickly how to support the person with an eating disorder.

The focus with carer peer support is often on practical knowledge and strategies such as how to frame the problem at hand, what to do, tips and ideas on approaches that work more effectively, and how to make changes in the home environment. Families and supporters need to understand issues such as meal support options, boundary setting and distraction techniques. They are also frequently the representatives of hope for the person they support.

Peer support and education from people who have been through the process in their own lives helps families to learn about eating disorders and put strategies into practice early in the course of illness. Carer peer workers can connect people with the right information; translate information into the everyday context; help to relieve the pressure and fear; support improved communication between parent and child; and boost carer wellbeing and confidence. Peer consultants and educators assist health professionals to understand and respond to the challenges of recovery from an eating disorder.

There is limited evidence about carer consultants as it is an emerging sector (Paton & Sanders, 2011). The evidence that exists suggests that supporter peer workers help family members and other supporters by providing support during difficult times; sharing experience; supporting exploration of different options; and helping through grief and anger.



Eating Disorders Families Australia (EDFA) <https://www.edfa.org.au>



Paton, N., & Sanders, F. (2011). *Best Models for Carer Workforce Development: Carer Peer Support Workers, Carer Consultants, Carer Advocates and Carer Advisors*. Perth: ARAFMI WA.

“I had concerns before the meeting that my experience differed from M's experience, and in terms of complexity, I would not be very useful. However, there was much more commonality in our experiences than differences and the sense I got from the conversation was that she felt very heard and less isolated having a conversation with someone with intimate experience of the beast that is an eating disorder, how it transforms our child and the strength that is required to fight it.”

“I think that this session marked a significant turning point in this family's journey. I am aware that the parents of this young person have been much more confident in dealing with the eating disorder since this session. They seem more relaxed as a family with each other and, while aware that there is still much to be done, have a sense that it is going to be possible to overcome the eating disorder.”

CAMHS clinician



Victorian Centre of Excellence in Eating Disorders (CEED) (2014). White Paper: Carer Involvement Project. <http://ceed.org.au/resources-and-links>

“When the family is included in the recovery journey, the whole family system has an opportunity to review the way that it functions and can shift in order to support each other as well as the person who is unwell. Carer Peer Support Workers can encourage and demonstrate a more positive approach to mental illness and inspire, support and coach others to find their own healthy response to the situation. Working alongside clinical teams, they can equip families and close others with the skills to manage the situation. As part of the clinical team CPSWs are also a vital resource to help clinicians understand and work with carers and families who themselves are experiencing distress and confusion.” (Logie, McCormack et al., 2017)



Logie, K., McCormack, J., McAlister, R. and Kirker, A. (2017). Carer Peer Work: Using the Lived Experience to Support Others. www.health.wa.gov.au

Peer Work and Family Based Treatments

The behaviours that are addressed in eating disorder treatment are ones that happen multiple times a day every day. In order to recover, support is needed in this constant daily struggle with ordinary life activities. In mental health services, the focus of family peer support is often on supporting parents to be advocates for their child, assisting with service system navigation and being a 'listening ear' to help families process their own feelings and stress in response to illness. These are important for family peer work in eating disorders service settings but they are not usually the first need. For families being offered FBT or family-led refeeding, the first aim of carer peer support is to 'galvanise' focussed and effective support for the young person.

Working through FBT is hard for families. It requires intensive involvement and commitment. Many families find FBT strategies to be counterintuitive, going against their understanding of the parent role with a teenaged child or young adult. Often the role of the peer support worker is to stretch the limitations set by parents on what they need to do, e.g. parents may need to remove bathroom/bedroom doors when that feels like an invasion of privacy.

There are a range of typical concerns for parents which can interfere with treatment such as fear of losing their relationship with their child and difficulty tolerating distress in their child. They often need to hear from someone who has been there that the behaviours they are seeing are time limited and generally resolve with recovery. The family need to be convinced that this is the right way forward. Peer workers who can draw on their own and other people's practical experience are able to inform and inspire families through this difficult process. In a way, the peer worker becomes an advocate for the treatment model and the clinical team, helping families to understand what is happening and to work with the treatment approach.

Carer peer support relies on the worker having lived through the experience of doing FBT as it involves practical considerations which may not be apparent to someone who hasn't been through it, such as meal preparation and support. This can be a crucial knowledge and skill set for families. They need skills in at-the-table meal support in terms of what to say or not say. They may need information and support on the increased and significant nutritional requirements of someone in recovery from an eating disorder.

Other skills families may need to develop include interruption or distraction techniques for eating disorder behaviours, strong boundary setting, and compassionate communication which at times looks 'weird' to other carers/parents, e.g. not going to school if haven't finished breakfast, pulling someone from a sport they love, eyeballing a teenager 24/7, or requiring food intake. It is important to support families to set boundaries around inappropriate violence and verbal abuse when a person with an ED is in high distress, by having a clear plan to manage this with appropriate back up from emergency services. There is a strong element of psychoeducation in this form of peer support, or a 'translational' role of the evidence, neurobiology and effective strategies.

Peer Work Outcomes



“Peer support and peer specialists complement and increase effectiveness of traditional mental health service models” (SAMHSA, 2012).

Peer work is recovery-oriented and has the potential to embed recovery principles in treatment practice, reduce the severity of relapse and consequent hospital admissions (Lawn, Smith & Hunter, 2008), and reduce the negative consequences of stigma for people with lived experience and their families (Repper and Carter, 2011). A systematic review found that peer work led to significant improvements in self-efficacy, empowerment, hope, self-esteem, agency, self-management and social inclusion with the people they worked with (King & Simmons, 2018).

Peer work contributes to measurable recovery outcomes by:

Peer Work Activity	Measurable Outcomes
Supporting engagement and commitment to treatment	<ul style="list-style-type: none"> – Rates of uptake of treatment – Retention rates – Motivation and hope for recovery – Symptoms of depression
Embedding person-centred and recovery-oriented approaches in mental health services	<ul style="list-style-type: none"> – Service user satisfaction – Service user participation rates – Commitment to recovery-oriented practice standards
Supporting self-directed recovery	<ul style="list-style-type: none"> – Reduced rates of relapse – Use of recovery planning tools – Improved use of natural supports and decrease in family stress (Thompson & Norman, 2008)
Reduction in re-entry to treatment	<ul style="list-style-type: none"> – Reduced symptoms of eating disorder – Reduced rates of re-hospitalisation – Reduced demand for intensive treatment
Reduced symptoms	<ul style="list-style-type: none"> – Reduced eating disorder behaviours – Improved personal recovery outcomes

There is evidence to support the efficacy of peer support for individual participants and in reducing service use and health care costs, however, the level of evidence for peer support and peer work in general mental health is moderate with few controlled trials (Gillard and Holley, 2014). The quality of evidence is poor by comparison with other health interventions (Lloyd-Evans, Mayo-Wilson, Istead et al., 2014). Much of the evidence comes from evaluation of programs in very different service settings, with different peer roles and different measures of outcomes (Chinman, George, Dougherty et al., 2014). These outcomes have not all been measured in eating disorder specific peer work programs.

There seems to be a gap between the anecdotal and evaluation evidence for peer work, which strongly supports the value of peer support, and the meta-analysis and controlled trial evidence which is more cautious in supporting the achievement of measurable outcomes. This may reflect the stage in development of peer work which is still in the early stages of implementation in mental health services, especially for eating disorders. It may also reflect the very personal nature of peer work.

There is a tendency for research to compare the outcomes of peer work interventions with those of clinical interventions (see for example Pitt, Lowe et al., 2013). This is not consistent with the concept of peer work as a unique role that adds value to but does not replace or compete with clinical treatment. Peer workers often take on roles, such as recovery support, that are not being carried out by health professionals, filling gaps in the continuum of care.



Davidson, L., Bellamy, C., Guy, K., & Miller, R. (2012). Peer support among persons with severe mental illnesses: a review of evidence and experience. *World Psychiatry*, 11(2), 123–128.



King, A. J., & Simmons, M. B. (2018). A systematic review of the attributes and outcomes of peer work and guidelines for reporting studies of peer interventions. *Psychiatric services*, appi. ps. 201700564.

Taking it Further



For more information and resources on peer work visit the Peer Work Hub. The Hub is supported by the Mental Health Commission of NSW.

<http://peerworkhub.com.au/>

Mental Health Service Standards

{ “Mental health consumer and carer identified positions are integral to recovery” (NMHCCF, 2010) }

Australian mental health policy requires mental health services to engage people with lived experience and their supporters in meaningful participation in all aspects of mental health services. Peer work roles provide one useful way of ensuring that this standard is met and that development of services is focused on the people who use those services (Byrne, L. Happell, B. and Reid-Searl, K., 2016).

The Australian Department of Health has recognised the value of a mental health peer workforce as a component of “quality, recovery-focussed mental health services” (Department of Health, 2015). The role of peer workers in the delivery of recovery orientated mental health services has been prioritised in recent reports and strategic mental health plans including the Fifth National Mental Health and Suicide Prevention Plan (2017). National standards for mental health services in Australia that prioritise participation of people with lived experience include:



National Standards for Mental Health Services (2010)

<http://www.health.gov.au/internet/publications/publishing.nsf/Content/mental-pubs-n-servst10-toc>



National Framework for Recovery-Orientated Mental Health Services (2014)

<http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-n-recovfra>



National Safety and Quality Health Service Standards

<https://www.nationalstandards.safetyandquality.gov.au/>

Each state government has also developed standards, plans or frameworks that prioritise increasing the peer workforce as a contributory factor for the improvement of mental health services. Peer work as it is described in this Guide is consistent with these mental health standards and frameworks and may be used as evidence in achieving these standards.

Document	Relevant Sections
NSW	
NSW Strategic Framework and Workforce Plan for Mental Health 2018-2022: A Framework and Workforce Plan for NSW Health Services https://www.health.nsw.gov.au/mentalhealth/resources/Pages/mh-strategic-framework.aspx	<ul style="list-style-type: none"> – Strategic direction 5: Building a better system – including developing the mental health workforce, improving engagement with families and carers, growing and supporting a peer workforce – Action item 1.5 Strengthen MH leadership – Action item 2.2 Grow and support the emerging peer workforce – Action item 3.3 Improve consumer engagement with services – Action item 5.6 Ensure the workforce is capable and supported
Lived Experience Framework for NSW (2018), NSW Mental Health Commission https://nswmentalhealthcommission.com.au/resources/lived-experience-framework	<ul style="list-style-type: none"> – Whole document
ACT	
A Real Career: A Workforce Development Strategy for the Community Mental Health Sector of the ACT (2012). Mental Health Community Coalition ACT. https://www.forwardit.com.au/wp-content/uploads/2017/06/A-Real-Career_-A-Workforce-Development-Strategy.pdf	<ul style="list-style-type: none"> – Action items specific to peer work at pp 18 and 22.
QLD	
Shifting minds: Queensland Mental Health, Alcohol and Other Drugs Strategic Plan 2018-23. Queensland Mental Health Commission. https://www.qmhc.qld.gov.au/sites/default/files/files/qmhc_2018_strategic_plan.pdf	<ul style="list-style-type: none"> – Policy and service map (page 8). – Strategic Priority 2. Support the workforce (page 23). – Focus Area 3: Whole-of-system improvement (page 32).
Consumer, Care and Family Participation Framework. Queensland Health (2010).	<ul style="list-style-type: none"> – Reference to peer work at page 13, as one of the key themes from consumer consultation
WA	
Peer Work Strategic Framework. WA Association for Mental Health/ WA Mental Health Commission (2014).	<ul style="list-style-type: none"> – Whole document

Document	Relevant Sections
https://waamh.org.au/assets/documents/projects/peer-work-strategic-framework-report-final-october-2014.pdf	
Western Australian Mental Health, Alcohol and Other Drug Services Plan 2015-2025. WA Mental Health Commission (2015). https://www.mhc.wa.gov.au/about-us/strategic-direction/the-plan-2015-2025/	– Pages 156, 158
SA	
Mental Health Services Pathways to Care Policy Guideline (2014). https://www.sahealth.sa.gov.au/	– 4.1.9.1 The Peer Workforce – 4.1.9.2 Role conflict
VIC	
Victoria's 10-year mental health plan. Victorian Department of Health and Human Services (2015). https://www2.health.vic.gov.au/mental-health/priorities-and-transformation/mental-health-plan	– Action area: Build and support the best possible workforce (pp 23-24)
Mental health workforce strategy. Victorian Department of Health and Human Services (2018). https://www2.health.vic.gov.au/health-workforce/strategy-and-planning/workforce-strategy/	– Principle: recognising the value of lived experience of mental illness and recovery (p 11) – Objective 4: Co-design and co-delivery with consumers and carers (pp 22-23)
TAS	
Rethink mental health: Better mental health and wellbeing, a long-term plan for mental health in Tasmania 2015-2025. Tasmanian Department of Health and Human Services (2015). https://www.dhhs.tas.gov.au/	– Reform direction 1: Empowering Tasmanians to Maximise their Mental Health and Wellbeing (p 16) – Reform direction 2: A Greater Emphasis on Promotion of Positive Mental Health, Prevention of Mental Health Problems and Early Intervention (p 17) – Reform direction 9: Supporting and Developing Our Workforce (p 27)
NT	
Mental Health Service Strategic Plan 2015-21. Northern Territory Department of Health (2015). https://digitallibrary.health.nt.gov.au	– Priority Area 4: Enabling participation and engagement (p 19) – Priority Area 5: Developing our mental health workforce (p 20)

References

This document is a part of the **Developing a Peer Workforce in Eating Disorder Service Settings** suite of resources. A full list of references for this document may be found in Part A: Exploring the Evidence.



The National Eating Disorders Collaboration

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For a downloadable copy of this resource visit: www.nedc.com.au

The National Eating Disorders Collaboration (NEDC) is an initiative of the Australian Government Department of Health.