



Developing a Peer Workforce for Eating Disorders

Exploring the Evidence

Part A

The **Developing a Peer Workforce** review and suite of resources was commissioned by the National Eating Disorders Collaboration in 2018 and developed by Lesley Cook, Blackboro Associates Pty Ltd, and Dr Katherine Gill.

The National Eating Disorders Collaboration

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

Executive Summary

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. They include people who have personal experience of an eating disorder and family members and others who have experience of supporting someone with an eating disorder.

Peer work provides a non-clinical collaborative approach as an adjunct to clinical treatment. Connecting with others who have similar life experiences is expected to improve understanding and increase hope (Basset, Faulkner, Repper & Stamou, 2010) with a consequent improvement in engagement in treatment and a reduction in the severity of relapse (Lawn, Smith & Hunter, 2008; Sledge et al., 2011). Peer work is also expected to assist health professionals and services by embedding recovery principles in treatment practice, and reducing the negative consequences of stigma for people with lived experience and their families (Repper and Carter, 2013).

Peer work is recognised in literature and policy as an important component of recovery-oriented mental health care. Australian mental health standards and practice frameworks require 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 these standards are met (Byrne, Happell and Reid-Searl, 2016).

The implementation of peer work strategies in eating disorders has been relatively slow by comparison with other areas of mental health and there is a very small body of evidence on peer work for eating disorders. The evidence that does exist, however, indicates that the experience and outcomes of peer work are comparable to those found in general mental health settings. Identified benefits include increased hope, improved engagement with treatment and sustained remission of symptoms during the long process of recovery post treatment. For families, benefits include a reduction in stress, overcoming isolation, and increased sense of agency and efficacy as partners in the treatment process.

Peer work initiatives for eating disorders also identify challenges and barriers to peer work that are very similar to those found in the general mental health literature. Key areas of concern are lack of understanding of the peer work role (Kemp and Henderson, 2012), unsupportive work environments and maintaining personal mental wellbeing (Moran, Russinova, Gidugu et al., 2013). Introducing peer work into existing service delivery approaches requires complex change at the organisational level as well as in individual beliefs and practices (Repper, 2013). Achieving the benefits of peer work is dependent on organisational commitment to change and a skilled and supported peer workforce. Existing eating disorder peer programs in Australia provide examples of how these challenges can be managed for safe and effective peer work.

Peer work provides a potential solution to the challenges of engaging people with eating disorders in treatment and supporting their long-term recovery. It is not,

however, a simple solution; peer work requires a commitment to recovery-oriented practice and organisational change, together with strong support strategies for the peer workers. Implementing peer work roles without adequate support or commitment to the work environment changes required places the peer workers at risk and reduces the effectiveness of the approach.

The most persistent barrier to implementing a peer workforce in eating disorder services appears to be funding. Without a source of funding specific to peer workers, it can be difficult to implement this important adjunct to treatment. There is a need for further research to demonstrate the impact of peer work and for investigation of appropriate ways to integrate peer workers into treatment approaches without compromising the uniqueness of these roles.

This paper is Part A of a suite of resources that provide a guide to the development of a peer workforce for eating disorders. The guide outlines selected evidence from the general mental health sector and eating disorder peer work initiatives and provides practice guidance based on existing peer work programs in Australia. Part B explores the peer work approach and what sets it apart from other approaches to mental health care. Part C of this Guide explores how organisations can influence the safety and effectiveness of peer work programs and roles.



Figure 1: Organisational Steps Towards Safe Effective Peer Work

Mental Health Practice Standards

Involving people with lived experience of mental illness and their family members and other supporters in the design, delivery and evaluation of services is an essential practice standard for mental health services.

A Reliable Evidence Base

There is limited evidence for peer work in eating disorders services, but it is consistent with the well-developed literature from general mental health settings, suggesting that this provides a useful guide for peer work practice in eating disorder settings.

A Different Approach

Peer work draws on the worker's lived experience, applied in the context of the role to help others work towards recovery. Practice is relational and collaborative, focussed on the person and their goals for recovery.

Non-Clinical Adjunct to Therapy

The peer work programs that exist in eating disorders are non-clinical, providing support for people who are working through treatment or who have completed treatment.

A Recovery Oriented Work Environment to Achieve Outcomes

Peer workers need a work environment in which they are empowered, equipped and supported to put their unique approach into practice. This involves commitment to recovery-oriented practice, purposeful peer work roles, induction training, integration into the work team, and flexible supportive supervision.

Skilled Work

This is skilled work involving intense emotional labour. Competence is required in the foundational practices of peer work, including self-care. Peer workers also need a range of other skills to meet the needs of their specific job. Lived experience is essential for peer work but it is not a 'standalone' qualification for a peer work role.

Two Types of Skilled Roles

There are many different roles in the peer workforce but these fall into two core types:

Peer to peer roles in building a relationship with another person with an eating disorder (or a family member or supporter builds a relationship with another family); and

Lived experience consultancy roles in which the peer worker draws on their own experience and insights to provide education, information, or advice to health professionals, family members or other supporters.

The roles are not mutually exclusive but they do require peer workers with different skills and different motivation. Different training may be required to equip a peer worker to achieve in each role.

Matched and Time Limited

People with eating disorders need access to peer workers who are matched for experience and personal priorities. Access to peer to peer roles is limited to specific times and set durations of service to ensure appropriate boundaries are kept.

Measurable Outcomes

Peer work roles can contribute to measurable outcomes in areas such as:

- Increased hope, reduced shame and increased self-disclosure
- Engagement and commitment to treatment
- Sustained remission of symptoms and reduction in severity of relapse
- Embedding recovery-oriented practice in the organisation

Future Funding and Research

There is a need for funding to support the development of a peer workforce and for consistent evaluation of peer work initiatives in eating disorders to establish a stronger evidence base.

Purpose and Scope

The National Eating Disorders Collaboration (NEDC) commissioned the development of a Peer Workforce Guide, to promote and facilitate the implementation of evidence-based peer work in treatment and support services for people with eating disorders.

Issues to be addressed by the Guide include:

- How does experience of peer work in eating disorder settings compare with the evidence from general mental health settings?
- How can peer work safely contribute to recovery for people with eating disorders?
- How can peer workers with experience of eating disorders be supported to reduce risks to their own wellbeing?
- How can the benefits of informal peer relationships be translated into professional roles within the health system and within eating disorder treatments?

The focus of the Guide is on peer to peer work and specific issues related to eating disorders. This is the area of peer work that has the largest body of evidence relevant to eating disorders. The important roles of recovered clinicians and lived experience and supporter representation and advocacy are outside the scope of this Guide. The NEDC has previously published a guide to consumer and carer participation and the Stories from Experience resource which promotes safe and effective sharing from experience.

An NEDC Resource

The National Eating Disorder Collaboration (NEDC) is an initiative of the Australian Government Department of Health. Its primary purpose is to bring together all of the stakeholders in eating disorders prevention and treatment to develop a nationally consistent, evidence-based approach to eating disorders.

This Guide is a companion to the NEDC Service Implementation Guide (2014, revised 2017) and 'Competency to Treat Eating Disorders: A Workforce Development Blueprint' (2016). It is designed to be used with these publications to inform and support the development of eating disorder services.

As an NEDC publication, the Guide is informed by a review of the published evidence and by consultation with people with lived experience, their family members and other supporters, health professionals, consumer and carer organisations and researchers.

NEDC resource development follows a clear pathway from research evidence, to evidence from lived experience and clinical experience, to co-produced analysis and translation of that knowledge into standards and suggestions for practical action.

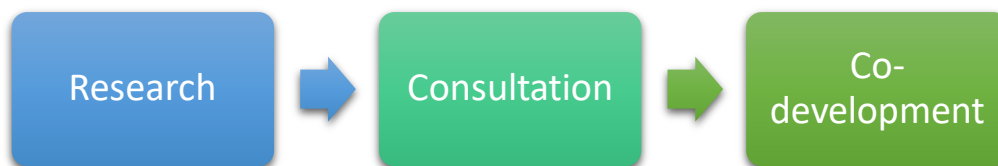


Figure 2: NEDC Resource Development Process

Expert Advisory Group

The Peer Workforce Guide has been developed collaboratively with national and state organisations representing people with lived experience of eating disorders and their families and with health service providers.

Organisations representing people with lived experience of eating disorders, families and other supporters and individual experts were invited to nominate members to join an Expert Advisory Group. The purpose of this group was to review evidence from the general mental health sector, share evidence from experience, and review the Guide during the development process.

Organisations Contributing to the Expert Advisory Group

Butterfly Foundation

Centacare South Australia (PACE Program)

Eating Disorders Families Australia (EDFA)

Eating Disorders Queensland (EDQ)

Eating Disorders Victoria (EDV)

National Eating Disorders Collaboration Steering Committee (NEDC)

Tasmania Recovery from Eating Disorders (TRED)

Victorian Centre of Excellence in Eating Disorders (CEED)

West Australia Eating Disorders Outreach and Consultation Service (WAEDOCS)

Women's Health and Family Services West Australia (Body Esteem Program)

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 four parts:

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

This document

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

Part B: Understanding Peer Work

Part B provides an introduction to peer work practices and the ways in which peer work 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 and evaluation of peer work initiatives. It may also provide useful content for training for peer workers and for clinicians.

C1. Co-design for Change

C2. Robust Recruitment

C3. Supporting Practice

C4. Introductory Learning Resources for Peer Workers

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A Personal Reflection on Peer Work

I developed an eating disorder in my teenage years during the 1980s. I didn't know I had an illness, my eating disorder thoughts were taking over, controlling me but they were a part of me, I thought they were just who I was. For decades I was caught up in disordered eating, excessive exercise, avoiding health professionals and hiding my behaviours and increasing health problems from my family and the health professions.

When I eventually went into treatment, I was told nothing about recovery, nothing about what recovery is, and how to get there. We were told recovery equated with weight gain. I thought if that is recovery then I don't want recovery. It would take me years of personal study, personal reflection and professional retraining to truly understand recovery. When I was going through treatment, I never had the opportunity to connect with peers or peer workers.

There is no one way to recover; there is no right or wrong way to recover. Treatment of eating disorders has frequently been a 'one size fits all', yet it didn't fit many. I really needed someone who had been on this journey before me, who could relate to my needs, my fears and explain to me that recovery is more than weight gain and that I can be more than a number on a scale. I needed someone who understood my journey and who could give me tools and strategies that they had used to support their recovery. I needed someone who could hold hope for my future, when I had no hope. I needed someone who could be there with me and who could sit with my pain, my helplessness and who understood what I was going through.

While this was never available for me, the rising profile of peer work across mental health has the potential to make a significant difference to the recovery, wellbeing and the life journeys of people experiencing eating disorders and mental ill health. Peer work is the missing link in the recovery process. Peer workers embody recovery; they know the experience, as they have lived the experience and they have skills and knowledge in the recovery process. Peer workers have been there before and can support others on a similar journey.

Peer work is about relationships, the unique bond formed between people who have experienced similar adversities. Peer work is about connectedness, connecting with a person who understands the unique journey and the battleground of an eating disorder. No one can truly understand an illness unless you have been on that journey. Peer workers have been on the journey of recovery, and they share this journey with meaning and purpose to help others come through their journey of illness towards recovery. Peer work is about growth through adversity, making meaning of a traumatic experience and period in one's life, and harnessing one's resilience and strength to come through the experience and to grow through and beyond the experience. When engaged in peer work, peer workers have to go further in their recovery journey than they ever thought possible.

Peer work is about adaptability, meeting the person where they are at, with no judgement. We understand the messiness of eating disorders; we understand the

horrors, the behaviours, the complexities and all the things you wouldn't tell other people about. Peer work is about meeting the needs of the person, without forcing people to fit into tight, neat boxes. We see the person as a whole person, with good and bad life experiences, with strengths, talents and weaknesses. We work with the person on their life path; we harness their strengths to help them towards recovery. We are with the person on their unique recovery journey; we don't require the person to be anything they are not. We are there to offer support, guidance and to share what helped and didn't help us on our recovery journey.

When peer workers are supported to use all their skills, knowledge and experience in a synergistic and holistic manner, they become powerful facilitators for recovery in people, who the system gave up on or whom the system failed to help. Peer workers are invaluable in the recovery process for eating disorders. We need to harness the power of peer support, and support peer workers to support others. Peer workers need to be recognised as an important provider of support for recovery in eating disorders. Peer workers need to be valued for the important role and potential they have to play in the Eating Disorder sector.

My hope is that barriers, stigma and discrimination of people with lived experience will start to erode and that peer workers and professionals with lived experience can bring their whole self when supporting people through one of their most difficult life journeys. When recovered individuals work with people battling eating disorders, we / peer workers / people with lived experience, bring a unique perspective to help people see a way out of the eating disorder battleground. We can sit in the distress of others, we can help people make sense of their illness and help people battling eating disorders, and their families, see light at the end of the tunnel. We can help them reach the light at the end of the tunnel.

Peer workers are a powerful recovery tool; let's harness the power of peer support in Eating Disorders.

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Consumer Researcher

Peer Worker

Disability Advocate

Manager

Occupational Therapist

Research Scientist

Biochemist

Person with a Lived Experience of Eating Disorders, Suicidal Ideation, Mental Illness and Recovery

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 considerably, including familiar terms such as consumer, carer, service user, and client. These are all terms in current use that appear in relevant practice standards and guidelines. The terminology used in this resource reflects this diversity of terms. We have not tried to impose a best-practice standard of language.

We acknowledge that 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 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 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).

A National Focus on Lived Experience

"The lived experience and insights of people with mental health issues and their families are at the heart of recovery-oriented culture."

- National Framework for Recovery-Oriented Mental Health Services (2013)

Peers supporting peers has a long and established history in the mental health and drug and alcohol arena (World Services AA, 2001). Peer support starts from an assumption that people who have overcome challenges, such as mental illness, are uniquely placed to provide support and inspire hope for others facing similar experiences (Davidson, Chinman, Sells and Rowe, 2006). Evidence for the effectiveness of peer work is emerging, with a strong indication that engaging a peer workforce in mental health services will improve outcomes for people who use mental health services (Pitt, Low, Hill et al., 2013).

The potential benefits of peer support have led to a profession of peer workers who are trained, employed and paid to use their lived experience of recovery to support others through their recovery. 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, Happell and Reid-Searl, 2016).

The Australian Department of Health has recognised the value of a mental health peer workforce as a component of recovery-focussed mental health services (see, for example, the National Framework for Recovery-Oriented Mental Health services referenced below). The role of peer workers in the delivery of recovery-oriented 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-Oriented 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/>

"Mental health consumer and carer identified positions are integral to recovery."
(NMHCCF, 2010)

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.

NSW

NSW Strategic Framework and Workforce Plan for Mental Health 2018-2022: A Framework and Workforce Plan for NSW Health Services

Relevant Sections:

- 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 mental health 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

<https://www.health.nsw.gov.au/mentalhealth/resources/Pages/mh-strategic-framework.aspx>

Lived Experience Framework for NSW (2018), NSW Mental Health Commission

<https://nswmentalhealthcommission.com.au/resources/lived-experience-framework>

ACT

A Real Career: A Workforce Development Strategy for the Community Mental Health Sector of the ACT (2012). Mental Health Community Coalition ACT.

Relevant Section:

- Action items specific to peer work at pp 18 and 22.

https://www.forwardit.com.au/wp-content/uploads/2017/06/A-Real-Career_-A-Workforce-Development-Strategy.pdf

Queensland

Shifting minds: Queensland Mental Health, Alcohol and Other Drugs Strategic Plan 2018-23. Queensland Mental Health Commission.

Relevant Sections:

- Policy and service map (page 8).
- Strategic Priority 2: Support the workforce (page 23).
- Focus Area 3: Whole-of-system improvement (page 32).

https://www.qmhc.qld.gov.au/sites/default/files/files/qmhc_2018_strategic_plan.pdf

Consumer, Care and Family Participation Framework. Queensland Health (2010).

Relevant Sections: Reference to peer work at page 13, as one of the key themes from consumer consultation

Western Australia

Peer Work Strategic Framework. WA Association for Mental Health/ WA Mental Health Commission (2014).

<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).

Relevant Sections: pp 156, 158

<https://www.mhc.wa.gov.au/about-us/strategic-direction/the-plan-2015-2025/>

South Australia

Mental Health Services Pathways to Care Policy Guideline (2014).

Relevant Sections:

- 4.1.9.1 The Peer Workforce
- 4.1.9.2 Role conflict

https://www.sahealth.sa.gov.au/wps/wcm/connect/010ec8004428c517aa1fffb3ef7a0fe8/Guideline_Pathways+to+Care_Policy+Doc_June+2014.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-010ec8004428c517aa1fffb3ef7a0fe8-msgMplQ

Victoria

Victoria's 10-year mental health plan. Victorian Department of Health and Human Services (2015).

Relevant Sections:

- Action area: Build and support the best possible workforce (pp 23-24)

<https://www2.health.vic.gov.au/mental-health/priorities-and-transformation/mental-health-plan>

Mental health workforce strategy. Victorian Department of Health and Human Services (2018).

Relevant Sections:

- 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)

<https://www2.health.vic.gov.au/health-workforce/strategy-and-planning/workforce-strategy/mental-health-workforce-strategy>

Tasmania

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).

Relevant Sections:

- 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)

https://www.dhhs.tas.gov.au/_data/assets/pdf_file/0005/202496/DHHS_Rethink_Mental_Health_WEB.pdf

Northern Territory

Mental Health Service Strategic Plan 2015-21. Northern Territory Department of Health (2015).

Relevant Sections:

- Priority Area 4: Enabling participation and engagement (p 19)
- Priority Area 5: Developing our mental health workforce (p 20)

<https://digitallibrary.health.nt.gov.au/prodjspuj/bitstream/10137/988/1/Mental%20Health%20Service%20Strategic%20Plan%202015%20-%202021.pdf>

Evidence Review Process

The review process informing the development of this Guide included:

1. A scan of peer-reviewed literature to identify the evidence for peer work and/or peer mentoring in eating disorders;
2. A survey distributed through the NEDC and state consumer and carer organisation networks, targeting peer workers and people who have received peer support for eating disorders, and clinicians who have worked with peer workers in the eating disorder sector in Australia; and
3. Interviews with peer and non-peer staff involved in the delivery of selected eating disorder peer specific programs in Australia.

A literature search targeting peer work and eating disorders was conducted in August 2018 using the medical and health sciences databases including ProQuest Central, OVID Medline, PubMed, AMED (Allied and Complementary Medicine), EBM Reviews and PsycARTICLES. The search terms were 'eating disorder' AND 'peer work' or 'peer mentor'. The search involving 'eating disorder' AND 'peer work' identified 1351 articles and the search for 'eating disorder' AND 'peer mentor' identified 194 articles. The titles and abstracts of the identified articles were screened against the inclusion criteria, being:

- Inclusion: Reports on eating disorder treatment involving peer workers or peer mentors
- Inclusion: Peer reviewed, full text article available in English
- Exclusion: Prevention of eating disorders, or programs focused on self-esteem/body image
- Exclusion: Reporting on peer influences including peer pressure, peer victimisation, peer friendships or 'pro ana'

A manual search for articles using google scholar was also conducted. A total of seven articles and two conference abstracts met the inclusion criteria. A larger number of articles captured the use of peer mentors in programs that targeted prevention of eating disorders or peer mentoring related to body image or self-esteem, however these topics were outside the scope of the project. No literature was found which addressed the role of lived experience or carer consultants within any eating disorder setting.

The research and conference papers reported on four peer programs for eating disorders in Australia (Ramjan et al., 2018; Ramjan, Hay and Fogarty, 2018; Beveridge et al., 2018; Purcell et al., 2014; Wade et al., 2014), one in the United States (Perez, Van Diest and Cutts, 2014) and two in the United Kingdom (Cardi et al, 2015; Cardi et al, 2017). Many of these research articles were based on pilot trials. Two of these programs, one peer mentoring program in New South Wales (Ramjan et al., 2018; Ramjan, Hay and Fogarty, 2018) and one in the USA (Perez, Van Diest and Cutts, 2014) are no longer operating and it is not known if the Western Australia child and

adolescent program is still operating. The two articles from the United Kingdom (Cardi et al, 2015; Cardi et al, 2017) and one from Victoria, Australia (Beveridge et al., 2018) reported on the program design and study protocol that incorporated peer expertise but the outcomes for these programs are not yet available. Only one program from Western Australia targeted children and adolescents (Wade et al., 2014) with the remaining programs being for adults over 17 years of age.

The dearth of published research reporting on the use and outcomes of peer work in eating disorders, relative to the published literature on eating disorders, suggest that research into peer work is a new and emerging concept.

For comparative purposes, a framework was developed of expectations and practices in peer work in general mental health settings, based on published literature reviews and relevant state and national frameworks or standards established.

Given the limited research evidence available, the methodology for this project was extended to include direct input from people with lived experience working as peer workers and from organisations currently providing eating disorder peer work programs in Australia. Providers of peer work services were identified through the published literature on evaluations and current trials. All known consumer and carer organisations providing eating disorder peer work at a state or national level were invited to participate.

A survey on peer work was distributed by the National Eating Disorder Collaboration and state-based consumer and carer organisations to identify knowledge, attitudes, benefits, challenges and barriers in relation to peer work in eating disorders in Australia. The survey captured the perspective of clinicians who have worked with peer workers, peer workers and people who have been the recipients of peer work.

Managers and peer workers involved in eating disorder peer work programs were interviewed about their experiences of peer work. The interview outcomes aligned with the literature and survey outcomes. The service providers highlighted the steps they undertook to ensure the wellbeing of the peer mentor and mentee, and eliminate the risk of relapse and the peer mentor being triggered. With structures and support put into place it was reported that mentors were not negatively impacted by their role, and that the mentors reported positive experiences and personal growth through their role as a peer mentor.

Peer Work and Recovery from Eating Disorders

“Recovery-oriented mental health practice 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.” (National Framework for Recovery-Oriented Mental Health Services, 2013)

Many people with experience of eating disorders feel that their understanding of recovery is different to that of their treatment providers and their family (Butterfly Foundation, 2016; Offord, Turner and Cooper, 2006).

“The challenging behaviours of eating disorders are entrenched in daily life, specifically around meal times, and cannot be avoided. Assistance during every-day living can make the difference between recovery or not.” (NEDC, 2017)

“Eating disorders occur in the context of a person's life. How the person understands what is happening to them, how they feel physically, how this impacts on relationships and daily activities all makes a difference to the way they experience treatment and recovery.” (Cook and Morgan, 2016)

People who have recovered from an eating disorder see themselves as the active agents in their recovery (Nilsson & Hagglof, 2006) and identify broadening life activities as a factor in sustaining recovery (Björk & Ahlström, 2008). The Insights in Recovery qualitative research project (Butterfly Foundation, 2016) investigated the experiences and retrospective insight of people who self-identified as recovered from an eating disorder. Results from this study indicate that personal factors such as relationships and developing coping strategies and meaningful life activities play an important role in achieving and sustaining recovery. Making new social connections and building positive relationships was the factor most commonly identified as contributing to recovery (Butterfly Foundation, 2016).

“Recovery is a complex process with no single ‘correct’ pathway. Recovery-oriented approaches in treatment aim to support individuals in taking responsibility for their personal journey to recovery and offer a collaborative holistic framework to work within. This is a process that requires more than clinical treatment. People with eating disorders identify a range of factors that contribute to recovery including personal relationships, meaningful activities and positive life experiences.” (Butterfly Foundation, 2016).

“People who have realistic expectations of life in recovery are more likely to sustain their recovery than those who do not anticipate the challenges ahead of them.” (Federici & Kaplan, 2008)

People with eating disorders report intense feelings of fear and shame, lack of control and feeling disconnected from others and their world. To address this, they identify a need for the following experiences as foundations for their recovery:

- **Safety:** feeling safe, in a non-judgemental environment with people who they can trust and accept feedback from
- **Disclosure:** opportunities to talk through the whole of their experience and feelings
- **Hope:** belief that change is possible for them; motivation and persistence through the effort and challenges of recovery
- **Identity:** understanding self as something more than illness; self-acceptance; and integration of the experience of illness and recovery as part of their connected life journey
- **Connection:** social connection with others with similar experience as a platform for improving broader social connections
- **Choice:** to be an active agent in their own recovery by making their own choices when it is safe to do so
- **Skills:** learning the practical self-care skills and the recovery practices needed to live well (Butterfly Foundation, 2016; Cook and Morgan, 2017).

This is consistent with the conceptual model of recovery processes essential for personal recovery developed by Andresen, Oades and Caputi (2003, 2006 & 2011):

- Finding and maintaining hope and having a sense of personal agency
- Development or re-establishment of positive identity
- Building a meaningful life beyond illness
- Taking responsibility and control.

Peer workers are able to directly address these needs by using the unique tools and approaches of peer work.

Engaging with Treatment

Recovery from an eating disorder is both clinical and personal. The work of re-discovering or creating a meaningful identity and life, parallels symptom remission and may continue long after clinical recovery has been achieved. Personal and clinical recovery are two separate but interwoven strands of activity (Cook and Morgan, 2016).

Factors influencing treatment outcomes include engagement with treatment, drop-out rates, and sustaining treatment outcomes post treatment. People living with mental illness are often reluctant to engage with treatment and dropout rates are generally high, possibly due to difficulties in relationships with perceived authority (Dixon, Holoshitz and Nossel, 2016). Motivation to introduce peer work as an adjunct to treatment may be found in the relationship between peer work and service user levels of hope, commitment to treatment and their ability to access support for the maintenance of treatment outcomes during the long process of recovery.

Approximately 50% of people clinically recover from their eating disorder, demonstrated by an absence of symptoms (NEDC, 2012), taking an average seven years to achieve full recovery (Strober, Freeman & Morrell, 1997; Wade et al., 2006).

Relapse and recurrence are significant issues, with rates of relapse ranging from 22% to 51% across studies of people with anorexia nervosa and bulimia nervosa (Keel et al., 2005).

Premature drop-out from treatment for eating disorders is common, with research finding rates between 20.2% and 51% for inpatient treatment and between 29% and 73% for outpatient treatment (Fassino, Piero, Tomba and Abbate-Daga, 2009). Concerningly, rates of drop-out appear to be increasing (Ribnick, 2012). The reasons for drop-out have not yet been defined, although there are indications that the type of disorder and psychological traits may play a role (Fassino et al., 2009; Morlino, Pietro, Tuccillo et al., 2007). The relationship between the person and their therapist has been identified as a possible contributory factor (Morlino et al., 2007). A focus on the person rather than eating disorder symptoms, on developing self-awareness and on choice has been shown to reduce drop-out rates during the first weeks of treatment (Vandereycken, 2009). These approaches are consistent with the practices of peer work.

Lack of social support and feeling misunderstood contribute to feelings of isolation and frustration (Federici & Kaplan, 2008) which can be barriers to recovery. The support of someone who has come through the challenges that are characteristic of an eating disorder and can relate to the difficulties of creating healthier habits without judgement or threat can facilitate the motivation for change in the person. People with eating disorders often feel isolated and misunderstood by others. Use of person-centred approaches, including peer work approaches, shows promise as a means of improving engagement and compliance with treatment (Dixon et al., 2016). The ability of a peer to relate to these feelings has the potential to be a motivating and sustaining factor for recovery.

Accessing Peer Support

Of the 104 participants in the Insights in Recovery research, only 8.8% had the opportunity to engage with formal peer support (Butterfly Foundation, 2016). In the absence of a peer workforce, informal peer support networks amongst people experiencing eating disorders have formed organically and include online and face to face support groups, and 12 Step programs such as 'Over Eaters Anonymous' and 'Anorexics and Bulimics Anonymous'. When positive peer networks are not available, people with eating disorders may connect with groups that provide the sense of belonging in a way that reinforces eating disorder behaviour. The 'pro ana' movement has grown stronger with social media, online forums, Instagram and YouTube. The existence and power of negative peer support networks may have hindered the growth of positive peer support and peer work roles in the field eating disorders.

People who have recovered from an eating disorder recognise that some peer relationships have the potential to sustain the eating disorder rather than support recovery. The solution they propose is to create intentional peer relationships between peers who are well matched and supported by supervision (Butterfly Foundation,

2016). Developing supportive relationships and increasing a sense of belonging are identified as contributory factors in motivation for eating disorders recovery (Federici and Kaplan, 2008). Peer work actively contributes to achieving recovery outcomes for people with eating disorders and their families and carers.

“Often the mentor is the first person they have met who has recovered from an eating disorder. This is much stronger than just hearing about the concept of recovery. No-one is judging you in a peer relationship. There are no treatment rules. This is a safe space for self-expression. Mentoring is complementary to treatment. It is a practical approach outside the scope of the treating clinician.” (NEDC Interviewee, Service Organiser)

The Peer Support Charter

“The peer support approach promotes a wellness model. Assisting a person to find and develop their own personal resources empowers the individual with the belief that they can and do have control over their life. For people with mental health issues, being ready and willing to take on responsibility for their own journey towards health and well-being is a fundamental part of recovery. For carers, knowing that they have resources and skills to be able to support a person on that recovery journey can alleviate stress and improve their own health and wellbeing, as well as that of the person they are supporting.”

www.peersupportvic.org

Peer Work in Eating Disorders: What is the Evidence?

Peer Work in General Mental Health Settings

The general mental health literature identifies that, when peer work roles are well designed as part of an organisational commitment to recovery-oriented practice, they provide a “powerful resource” enabling organisations to remove barriers to engagement in treatment and sustaining recovery (NMHCCF, 2010). A systematic review of peer work found that this approach contributes to significant improvements for service recipients in self-efficacy, empowerment, hope, self-esteem, agency, self-management and social inclusion (King & Simmons, 2018).

Achieving these benefits requires a strong and supported peer workforce (Byrne, Happell and Reid-Searl, 2016). The safety and effectiveness of peer work is directly influenced by appropriate job roles, effective recruitment, workplace culture, provision of ongoing support to the peer workers and integration of peer work with the service's strategic commitments (Gillard and Holley, 2014). When these organisational strategies are not in place, the literature consistently identifies challenges for peer workers in misconceptions and inappropriate expectations about their roles, negative attitudes from other health service staff (Vandewalle, Debyser, Beeckman et al., 2016), and workplace cultures that sustain stigma and marginalisation of lived experience (Gee, McGarty and Banfield, 2016).

Investigating Peer Work in Eating Disorder Settings

Expectations based on the general mental health literature were compared with the available evidence for peer work in eating disorder service settings.

Nine peer programs were reviewed in the development of this Guide. All of the programs reviewed have a personal recovery focus using one or a combination of mentoring, education and supported self-help strategies. All were designed to offer additional support to the recipient in conjunction with an eating disorder treatment program or psychological services. Representative peer workers and organisers from four of these programs were also interviewed via videoconference, to add depth to the understanding of the practices that contribute to safe and effective peer work.

A total of 94 responses were received to the survey distributed to NEDC members and the membership of state and national consumer and carer representative organisations. Forty-four peer workers responded to the survey, 31 clinicians and 19 people who had received peer work services. All states were represented in the feedback, with the largest response received from Western Australia (43% of total). No responses were received from the Northern Territory and the Australian Capital Territory. This review found no evidence of formal peer work initiatives for eating disorders in the Territories.

Benefits of Peer Work to Recipients

The evidence specific to eating disorders indicates that peer support can be effective in reducing social isolation (Dearden and Lee, 2013), reducing feelings of shame and stigma (Chinn and Caswell, 2014), strengthening relapse prevention and helping families to understand eating disorders (Shepherd, Bennet and Monty, 2013).

The programs reviewed for this Guide all identified significant and positive benefits for the peer mentoring/peer support intervention. Key themes associated with the value of peer work for the recipient included hope, and feeling heard, validated and understood. The connectedness and relationship between the peer workers and recipient helped to reduce the isolation experienced by people with eating disorders and helped the recipient to normalise life activities and develop a life outside the eating disorder. Peer mentors engaged clients in normal daily activities and social outings and offered strategies and ideas to help overcome the eating disorder. Peers modelled recovery and represented evidence to both recipients and staff of eating disorder treatment programs that recovery is possible.

The most common theme identified by interviewees and in the published evaluations of these programs was a significant increase in hope and motivation for recovery experienced by the recipients of peer support. The objectives and measured outcomes of the projects considered in this review suggest that the benefits of peer work roles in eating disorders include:

- Improved hope for recovery
- Improved sense of belonging and social connection
- Practical life skill development
- Improved quality of life
- Increased self-efficacy
- Decreased eating disorder behaviours and thoughts
- Reduced drop-out rates from treatment
- Reduced rates of and severity of relapse
- Improved understanding of eating disorders and confidence to work with people with these disorders for clinicians, families and other supporters.

Hope, Understanding and Connected Conversations

These themes are consistent with the themes identified through the NEDC survey. The dominant themes found in survey responses were hope and understanding, with each word used 40 times in survey responses. 'Hope' related to the authenticity of the peer worker as a model of recovery and the practical, achievable strategies they focussed on. Peer workers were described as a source of inspiration to those working through recovery from an eating disorder and the family and staff supporting people with an eating disorder.

'Understanding' described the way recipients of peer support felt in relationship with peer workers. Behind the concept of understanding sat a range of terms familiar from the literature on eating disorders and mental health in general: non-judgemental, safe space, acceptance, comfort. These experiences contributed to

the person's willingness to disclose their experiences and to start to work on their personal recovery.

“What we offer is the soft skills of engagement – something that clinicians can't offer. Work with the person and ‘hold’ them; we don't work with the illness”. (NEDC Interviewee, Peer Mentor)

A third theme, identified as 'connected conversations' was also identified in the survey responses. The idea of disconnected conversations between people with eating disorders and clinicians was raised in the Insights in Recovery research (Butterfly Foundation, 2016). In this review, people used terms such as 'missing link', 'gateway relationship' and 'bridge,' all referring to the opportunity found through peer work to improve understanding and communication between the person, the clinical team and the family. Peer workers represent a point of connection to strengthen trust and confidence in relationships with clinicians and in personal relationships. The peer worker relationship can help ensure that the client outcomes are more rounded and recovery focused. Peer workers were reported to offer a sense of companionship and friendship in a way that clinicians were not able.

Peer workers helped the person to feel heard, understood and validated, and were able to offer insight and strategies to help the person on their recovery journey. Peers were reported to be able to encourage the individual not to give up and to adhere to their treatment plan. Peer work was seen as powerful and beneficial to all parties, helping to reduce the isolation associated with eating disorders and complex mental illness and supporting clients to navigate complex systems.

The benefits actually recorded for each program varied depending on the program objectives and the measures used.

Survey Feedback: Value of Peer Work

“I believe sharing life experiences helps create a bond and a level of comfort for those struggling with an eating disorder. Knowing someone has been through what you are going through makes conversations less intimidating and you feel like you are not being judged. I think these are great benefits and contribute in such a positive way to the treatment and recovery.” [Q7, no 42]

“The main contribution and benefits peer workers provide is a narrative of acceptance and hope that whilst recovery is not linear and can include relapse it is possible to recover. It also provides encouragement and growth for the peer worker to be able to use an experience they have had to benefit others.” [C, Q4]

“Peer workers are usually able to build rapport quicker and can 'speak the language' of EDs. This means that they are often able to identify things which may otherwise be missed or by other health care professionals. Peer work adds a dimension to holistic treatment models which is unable to be replicated by other means. Benefits: Good outcomes, connection, can assist with treatment

engagement, brings people out of isolation, offers hope and inspiration to others, huge potential as an area of expansion." [Q7, no 59]

"They offer the most authentic viewpoint and provide a crucial gateway relationship because they genuinely 'get it'. The benefit of this is that the client really feels 'heard'." [Q7, no 43]

"I feel they are the missing piece to a lot of treatment across the board. Peer workers have a unique knowledge from their experience, and when trained and supported well they can promote engagement in treatment, and hope." [Q7, no 52]

"The intimate and authentic knowledge of eating disorders from personal experience plus knowledge gained from training puts the peer worker or recovered coach in a unique position to support sufferers in recovery. In no way do peer workers or coaches replace therapists but as part of the multi-disciplinary team they are integral and vital. This has been a huge gap in the treatment of ED in Australia." [C, Q4]

"Peer workers offer empathy, friendship and hope. Peers are the beacon of light that make the clinician-devised strategy seem conquerable, especially in the times where it is difficult to push on" [Q8, no 49]

Perceived Risks

Connecting with peers has at times been seen as a risk for people with eating disorders, with the potential to contribute to maintaining illness rather than recovery. Informal peer influence has the potential to encourage, intensify or sustain eating disorder behaviours, particularly in adolescents (Dishion and Tipsord, 2011; Marcos, Quiles, et al., 2012).

Beliefs and concerns held by clinicians include that peer workers are vulnerable and could be triggered, could relapse, and that there would be transference and counter-transference (Johnston, Smethurst and Gowers, 2005). Clinicians responding to the NEDC survey identified concerns about peer workers crossing boundaries, being triggered or enmeshed in their work with clients. Clinicians highlighted that peers needed to have appropriate boundaries and to have reached a state in their recovery that they not are triggered by individuals still in the depths of an eating disorder. Clinicians were concerned about splitting, with the client seeking 'refuge' with the peer worker. Clinicians were concerned that peers would provide advice around treatment that is not reflected by current practice guidelines or evidence-based treatment. Clinicians reported that they believed it would be difficult to find peer workers at a point in their recovery where they would not be triggered, and that it would be difficult to keep peer workers as their health would fluctuate.

The risks to recovered individuals employed as peer workers is an emerging focus of investigation and research. Issues of common concern identified so far include: negotiating boundaries for peer work roles that blur the boundaries between

friendship and professional support; role expectations, confidentiality and respect within the work team; exposure to stressful and potentially triggering events in an unsupported environment (Moran, Russinova, Gidugu and Gagne, 2013; Repper and Carter, 2013).

Concern about the risk of relapse is a potential barrier to the employment of peer workers that has not been sufficiently investigated, especially for eating disorder peer workers. For some, relapse is understood as a risk to the service user as well as the peer worker, as witnessing relapse may reduce hope and motivation for change for the service user (Repper and Carter, 2011).

Survey Feedback: Peer Workers reporting negative benefits to health and wellbeing

“At times it can be difficult and your own values can be challenged, but being able to support others through their own difficult times, and reminding them that recovery is possible, can be a very rewarding experience.” [Q11, no 53]

“Initially it was difficult to separate my illness from theirs and I found myself becoming more unwell because of it. Although, I persevered and framed my mindset differently (to more of a “I’m in a position to help these people” thinking style), and I found my role actually ended up motivating me to become more involved” [no 12]

“There are times when I enjoy working with people, but there are times when it does feel overwhelming to deal with other people’s issues” [no 46]

“Being a peer worker has good and bad aspects. In working in the role, you are making a commitment to sustain your recovery and wellbeing for yourself and others that can enhance recovery and learning. However, there is significant stigma, discrimination and undervaluation of peer workers in workplaces that can offset our efforts to recover and thrive at work. There is much more to be done to empower peer workers and, in doing so, empower the people using services in their recovery.” [no 37]

“My experience has been one of much struggle and stress in a misunderstood and under supported role. It has compromised my wellness at times. Peer workers have also not been supported by clinicians in this state and just given token recognition. The theory of our work is very different to the reality and much of this comes down to misunderstanding and a lack of resources and support in EDs in general. There are very few options for me to refer people on to so I wear a lot of the burden myself. I would not do this role again in its current incarnation.” [Q11, no 43]

The Peer Worker Perspective

While these concerns were expressed by clinicians, peer workers reported their employment experience as a mostly positive one which helped to solidify their recovery, make them more resilient, and enrich their health and wellbeing. Working as a peer worker gave the peers a sense of confidence and capability, and learning how to manage their stress made them stronger. Peer workers reported their role to

be uplifting, empowering and healing. The role empowered the peer workers to move forward and find value in their own experience and journey, and to use a traumatic personal experience to help support others.

While there was a strong sense of personal benefits associated with working in a peer role, survey responses also identified personal challenges. Some peers reported burning out quickly, that the role could be challenging, and at times it was difficult to separate their illness from the person they were supporting. Some peers reported that at times it could be overwhelming to deal with other people's issues and at times the role could be stressful. Peer workers also reported experiencing stress when they were exposed to discrimination and undervaluation of the peer worker role in the workplace.

The challenges identified by participants and organisers of the programs reviewed also reflect the general mental health literature on the challenges of peer work (see for example, Byrne et al., 2016; Vandewalle et al., 2016; WAPSN, 2018). Of particular note were:

- Negotiating boundaries for roles which blur the usual boundaries between informal relationships and professional service provision
- Developing clear role expectations and descriptions while maintaining flexibility in role activity
- Providing access to training and supervision to support safe and effective peer work
- Robust recruitment strategies and selection criteria relevant to the position and to safety concerns for peer workers and participants
- Finding adequate resources to support peer work initiatives.

The general mental health literature has found that lack of clarity around peer work roles contributes to stress and inappropriate usage of peer work roles (Byrne et al., 2016; Kemp and Henderson, 2012). A common conclusion in the literature is to provide clearer job descriptions (Jacobsen, Trojanowski and Dewa, 2012). The survey and interviews in this review allowed for clarification on the need for better position descriptions. Participants placed emphasis on purposeful roles that reflected the principles of peer work. Prescriptive task lists were not seen as helpful. Tasks emerge within the work environment and with each person receiving support; the gap in practice is in developing understanding of how peer workers achieve the goals of their work.

Resourcing and Supporting Peer Work

The employment of peer workers improves access to quality peer support, minimizes unintended consequences, and reduces stigma, however it also involves professionalisation of something that would otherwise occur informally between individuals. It relies on the ability to create relationships as equals in a service context in which there are perceived hierarchies and an imbalance of power between health professionals and service users.

The survey outcomes identified repeated concerns about the lack of funding for the peer role along with a lack of availability of positions. Funding was seen as the major limitation to peer work in eating disorder settings, along with a lack of training, learning and development for the peer worker, including peer supervision. Lack of adequate remuneration was identified as a significant problem and meant the profession was at risk of not attracting the most appropriate applicants/workers.

Survey Feedback: Limitations and Barriers

"The roles are casual, and therefore job stability is an issue. The pay rate for some positions is low. I am fortunate to have an open, respectful team at CAMHS but this may not always be the case in other organizations." [Q10, no 52]

"Main barrier is funding/award rates of pay. Hard to attract others to get involved - people usually have to accept a much lower rate of pay. There are a range of skills which are really helpful in peer work from interpersonal coaching, understanding of illness, health systems etc and people who have those already are usually earning more in a different job. Means you only get people who don't need to earn a living or prepared to do because so passionate." [Q10, no 36]

"No funding. No government leadership and commitment to investing in these roles. Governments not walking the talk when all stakeholders are on board that it's important." [Q10, no 37]

"Funding is a big limitation. As well as the amount of hoops we have to get through in order to do anything just a little bit different." [Q10, no 38]

"Limited resources and lack of community and health care provision" [Q10, no 41]

"Money to employ PSW's. We know and have evaluated how valuable they are to our programs - however, funding is challenging (especially in a private setting). Also, in regards to health funds, PSW's are not allowed to document in patient progress notes - therefore, they must have a health professional co-facilitator in all groups." [Q10, no 45]

Survey responses from peer workers indicated that there are insufficient employment opportunities in peer work. In contrast, some clinicians commented that it was a challenge to find peer workers. Clinicians also described peer work in terms of 'volunteering' and 'no cost'. The idea of peer workers as a low or no-cost approach is not consistent with the evidence, both from the literature and from peer work programs in practice in Australia. Peer workers need to be remunerated appropriately for their work, reflecting the intensity of emotional labour and the range of skills that they are expected to use in their roles (Byrne, undated). Peer workers require relatively intensive supportive supervision and opportunities for training and peer networking to enable them to practice safely and effectively (Byrne, undated). Clinicians require training and other opportunities to learn about peer work and its relationship to recovery-oriented practice. Peer work is a new way of delivering care; it is not a cheap solution.

Comparing Peer Work Across Sectors in Mental Health

The available evidence for eating disorders peer work aligns with the stronger evidence base for peer work in general mental health settings. General mental health literature and early evaluation outcomes of eating disorder specific peer programs suggests peer work roles can contribute to improved rates of retention in treatment, improved treatment outcomes and sustained recovery. They may also assist clinicians and family members by improving their understanding of these disorders and reducing the associated stress of supporting someone with an eating disorder. Challenges in establishing peer work roles and supporting peer workers within traditional health service systems are consistent across mental health fields.

Similarities between the experiences of peer workers, service organisations and service users across mental health settings suggests that it is appropriate to apply the general mental health literature to the development of peer work roles for eating disorders. This literature has therefore informed the peer work practice guide which is a companion to this paper.

This review did identify some areas in which the practice of peer work for eating disorders seemed to differ from other approaches to peer work, notably:

- **Recovery criteria for recruitment** – all peer programs reviewed required minimum wellness criteria for peer workers at the outset of employment, including the necessity for peers to be 18 months to 2 years into full recovery.
- **Adjunct to treatment** – peer support projects reviewed typically described themselves as adjuncts to treatment and identified clinical outcome measures as appropriate for the assessment of peer support outcomes.
- **Family and carers as peer workers** – the involvement of family members or other supporters in the treatment team placed a different emphasis on their training and support needs. This is reflected in the role of family or carer peer worker where the emphasis may be on the practical skills of supporting treatment in daily life. Access to a peer worker may be an urgent issue for families as they need to develop knowledge and skills quickly in order to support the person with the eating disorder.
- **Bounded relationships** – time limited engagement between the peer worker and the person being supported.

Peer programs in Australia provide good practical guidance on these issues and this has been taken into consideration in the development of this peer work guide. Further investigation of these apparent differences and their relationship to participant and peer worker safety is required.

Conclusion

The eating disorder literature, survey and interview responses, demonstrated consistent support for the value of peer work, with identification of the peer work role

in connecting with the recipient, offering empathy and compassion, and enabling both the recipient and the staff to recognise that recovery from eating disorders is possible. People with eating disorders, and their families and other supporters have expressed a desire to have the opportunity to work with people with lived experience (Butterfly Foundation, 2016). Well organised and supported programs are able to demonstrate that peer worker approaches can be safe and effective for both the peer worker and participants. Peer work programs in eating disorder services face the same challenges as peer workers in other mental health settings, however the organisational practices of peer programs in Australia demonstrate that these challenges can be effectively addressed.

The evidence from all sources indicates that peer workers feel empowered in their role, and that the role strengthened their recovery and their motivation to stay well. Concerns and barriers were identified, however, the practice evidence indicated that with the right supports, supervision, training and structures in place, peer workers were not at risk of relapse, and that many peer workers benefited from their role as a peer worker. This Guide addresses the issue of clarity around the peer work role and the type of organisation practices required to support peer workers.

Implementation of peer work roles in treatment and support settings holds the potential to improve recovery outcomes for people with eating disorders, making the most effective use of what we currently have available in knowledge and treatment approaches. However, implementing peer work roles without adequate support and commitment to the work environment changes required, places the peer workers at risk and reduces the effectiveness of the approach. The most significant barrier to implementation of peer workforce in eating disorder settings raised in this review related to lack of funding, opportunities, equal pay and clinicians not understanding and valuing the peer worker role. A further barrier is likely to be finding suitable peer workers. These barriers are replicated in the evidence for peer work in general mental health settings.

Given the very small number of published papers found in this review, further research is clearly required to examine the measurable outcomes and impact of peer work roles and programs. Ideally every peer work initiative in eating disorders would be evaluated using consistent and comparable measures. There is also a need to explore the diversity of peer roles, including the role of the recovered peer clinician. There are emerging resources in this field and some of these are referenced in Part C3 of the Guide.

Survey Feedback:

Peer Work is a Core Component of Care

"Peer workers should be a core component offered to all people with lived experience, their families and carers. I have a lived experience and found the absence of lived understanding and support from people of a similar age to me led to profound and ongoing isolation and conflict between me and the treating team, and similarly a lot of isolation, stress and despair for my family. Seeing people who are living well but know how difficult the journey can be, and what you might be experiencing, is important to feeling like you are not alone in the dark, cold torment of an eating disorder" (NEDC Survey Feedback, Q7, no 37).



"I have seen peer work embraced by previously reticent clinicians purely through exposure to and collaboration with a peer worker. Peer workers have the ability to compliment clinical practice and Vice versa. In isolation it is difficult but collaboratively, as I have discovered in my role, consumer outcomes can be more well-rounded, less medical and recovery-focused. I work with consumers who have a diagnosis of an ED in the program. Not only have I trained the nurse, I have supported the consumers and worked directly with their carers to instil hope. Peer work can work very well if it is implemented in the correct way and for the right reasons. To allay fears, get an experienced peer worker to sit down and discuss peer work with the team. I have done this with CYMHS and it went very well, we are now hiring peer workers to work in that space." (NEDC Survey Feedback, Q11, no 8]

Peer Mentor and Support Programs

The following brief descriptions of the peer work programs reviewed for this guide are based on published evidence and interview responses. These 'snapshots' introduce the type of peer work program that is most likely to be provided for eating disorders.

Programs in Australia

Instilling Hope for a Brighter Future Mentoring Program, Western Sydney University

Instilling Hope was a 13-week, time-limited mentoring program using volunteer (unpaid) mentors to provide an informal style of mentoring that included sharing activities together such as craft, shared meals, and social outings. The focus of interaction between mentor and mentee was establishing normal relationships and developing hope in an equalised power relationship. Mentors and mentees met at a workshop where they self-paired into the mentor-mentee dyad. The introductory workshop defined the roles and responsibilities, ground rules, support and communication, and processes for dealing with a relapse. An average of one hour per week contact was provided and a minimum of three face-to-face sessions were required.

Instilling Hope involved two research projects: the first involved individuals with anorexia nervosa (AN) being mentored by individuals who had recovered from AN. There were 5 mentors and 6 mentees in the program. 100% of the participants were female. The mean age of the mentors was 30.4 years and the mean age of the mentees was 26.8 years. 27.3% of the participants were married/de facto and 27.3% had children.

The second project involved individuals with any eating disorder being mentored by individuals who had recovered from any eating disorder. There were 10 mentors and 10 mentees in the program. Again, 100% of the participants were female. The mean age of the mentors was 28.9 years and the mean age of the mentees was 29.2 years. 60% of the participants were single and 10% had children. The mentors had recovered from AN (n = 7), a combination of bulimia nervosa (BN) and AN (n = 2) and a combination of binge eating disorder (BED) and AN (n = 1). The mentees had AN (n = 5), BED (n = 1), BN (n = 1), other specified feeding or eating disorder (n = 1) and severe and enduring AN (n = 2).

All participants completed questionnaires to monitor their wellbeing, including the eating disorder examination for symptoms (EDE-Q), Kessler Psychological Distress Scale (K10), functional health and wellbeing (SF-12) and the Global monitoring relationship questionnaire scale. The primary outcome measure for the program was hope, measured using the validated domain specific hope scale. Fortnightly log books qualitatively measured participant's health and the mentoring relationship. Based on the content of the logbooks the investigators would follow up with additional support or advice or the mentors could make contact directly for ongoing support and supervision.

The studies showed that the mentees experienced hope for recovery in both projects. The participants were enthusiastic about being involved in the program and contributing to the program design. The mentees felt that their mentors understood them and could relate to them without being judged. The relationships that developed were ones of trust, openness and communication, with the mentees feeling like they were about to slowly start to reconnect with the world and be challenged to change in a supportive environment. There was also an improvement in hope for the individuals with severe and enduring AN, which was encouraging as these individuals are often resistant to traditional treatments and they often experience poorer outcomes.

The mentors experienced insights into their own recovery and how far they had come and this reinforced their determination to not return to their eating disorder behaviours. The mentors were altruistic and wanted to help others. Importantly, the mentors were monitored throughout the study and experienced no change in mental health during the program.

Program evaluation identified a significant increase in hope for the mentees from baseline to post program. The mentors remained stable throughout the program. Thematic analysis of qualitative data identified five key themes 1. Instilling hope that recovery is possible; 2. The mentor could understand and relate to the mentee; 3. Reconnecting to the world; 4. Effective communication is the key to mentoring; and, 5. The mentor's altruistic motivations, transformation and the discovery of self.

The Instilling Hope for a Brighter Future projects were shown to be feasible with some helpful suggestions about how the project could be improved. Face-to-face communication was viewed as the most effective form of communication supplemented by text messaging and email. Text messaging or email was a tool that mentees used when the conversation was difficult or they felt intimidated in a face-to-face setting.

Both mentors and mentees felt that this type of program addressed a need in support that was not currently available and wanted the program to continue past the research phase.



Ramjan, L.M., et al., Instilling hope for a brighter future: A mixed-method mentoring support programme for individuals with and recovered from anorexia nervosa. *Journal of clinical nursing*, 2018. 27(5-6): p. e845-e857.

Peer Mentor Program - Eating Disorders Victoria

The Peer Mentor Program (PMP) pilot study was a collaborative initiative between Eating Disorders Victoria (EDV), The Melbourne Clinic (TMC), and the Body Image and Eating Disorders Treatment and Recovery Service (BETRS) at the Austin Hospital (inpatient unit) and St Vincent's Hospital (intensive day patient program) (Beveridge et al., 2018). From 2019, the program is now open to all Victorians, 18 years plus, from specialist eating disorder inpatient and day patient programs. The objectives of the PMP are to improve eating disorder symptomatology and the person's quality of life,

and to reduce rates of relapse in participants. The role of the mentor is to help the mentee understand what is happening and develop hope for the future.

Participants have experience of an eating disorder (all diagnoses) and have received treatment through one of the partner health services in an inpatient, outpatient or day program. PMP provides a step down from intensive treatment with entry to the PMP on discharge from the treatment service. The program provides 13 mentoring sessions of up to 3 hours each, delivered over an approximately six-month period.

Mentors are employees, engaged on a casual basis. Mentees and mentors are matched based on personal statements and preferences, and organisation capacity. Mentors are required to have a minimum of two years in recovery as indicated by clinical measures, including the absence of eating disorder symptoms (indexed by the EDE-Q), being weight restored and not receiving treatment for eating disorder symptoms. Mentors are required to have strategies to maintain wellness. The suitability of mentors and their level of recovery is assessed at interview and ongoing throughout the program. Mentees are required to be actively receiving treatment for their eating disorder for the duration of the program. Mentees work towards goals identified in their wellness plan. Mentors also complete a modified wellness plan that enables them to document self-care strategies and identify potential risks to ensure that staff can support them and ensure the mentor role is not detrimental to their health and wellbeing. Individuals at risk of harm or suicide are excluded from the program.

Key issues dealt with in mentoring include dealing with anxiety and stress; getting out into the community; figuring out other areas of life; and developing self-efficacy. Mentoring sessions provide an opportunity for people to take a break from focusing on their eating disorder, to regain a life that is not dominated by illness. Mentoring activities occur in community settings to meet the needs and interests of the participant and the peer mentor, e.g. shopping centres or cafes. Some sessions are held on the hospital ward when participants experience relapse. Meetings are not permitted in either person's home.

Evaluation of the program includes outcomes measures for eating disorder symptoms (EDE-Q), depression and anxiety scale (DASS), disability (Brief disability questionnaire), quality of life and feedback questionnaires. These were undertaken at baseline, three months, six months on program completion and at 12 months follow up. Qualitative analysis will investigate the experience of mentees and mentors identifying both positive and negative experiences. The program is ongoing and the outcomes not yet available at the time of writing.



Beveridge, J. Phillipou, A., Edwards, K., Hobday, A., Hilton, K., Wyett, C. et al., (2018). Peer mentoring for eating disorders: evaluation of a pilot program. Study Protocol. Open Access 4:75.

Body Esteem Program – Women’s Health and Family Services, Western Australia

The Body Esteem Program (BEP) is a 20-week, community-based, group education program facilitated by lived experience leaders, with a group sized capped at 13. Participant groups are not matched; each group is formed from the waiting list. A fee of \$350 is charged for the full program, paid up front – a factor which helps to keep participants engaged. Group participants have to be seeing an independent therapist at least once a month. This ensures the link to treatment if it is required.

The 20-week program is delivered for 2.5 hours once a week. The first 10 weeks focus on challenging eating disorder thoughts and behaviours, while the second 10 weeks branch off into other life areas which tend to impact upon the development and continuation of an eating disorder.

BEP aims to inspire freedom from an eating disorder by empowering women to work toward recovery through shared experience and support. BEP utilises lived experience facilitators to provide holistic, person centred programs that support women who experience eating disorders, and their families. Two separate programs are provided, one for women who identify with either Anorexia Nervosa or Bulimia Nervosa, and one for women who identify with Binge Eating Disorder. There is also a parent/partner education and support program.

Based on the Self-Help Model of care, BEP encourages participants to accept personal responsibility for working toward positive change in their own lives. A self-help approach recognises the importance of encouragement, emotional support, shared knowledge and positive social connectedness for those working toward recovery. BEP uses a holistic, strengths-based approach which promotes an understanding that life is experienced within a socio-cultural context and that these factors can influence the development and maintenance of, and also the recovery from, an eating disorder.

The program aims to assist participants to increase personal insight and coping strategies, develop personal resilience and take responsibility for their own recovery. Outcomes include reduced levels of secrecy, shame and isolation.

The BEP is conducting research, using both quantitative and qualitative program outcomes. Existing feedback results indicate that approximately 75% of participants report a decrease in their eating disorder behaviours post program, as well as increased levels of hope, insight and a reduction in feelings of isolation. Feedback suggests it is beneficial that facilitators are informed by lived experience and that they are able to model recovery positively.



Chinn, K. and Caswell, J. (2014). The Body Esteem Program: inspiring freedom from an eating disorder. *Journal of Eating Disorders*, 1 (Suppl 1): 62.

Reaching Out for Hope – Princess Margaret Hospital, Western Australia

The Child and Adolescent Mental Health Service (CAMHS) Eating Disorders Program (EDP), is a specialised service located at Princess Margaret Hospital. Reaching Out for Hope was initiated in 2013 as a collaboration between CAMHS EDP and the Body Esteem Program. The program specifically focusses on enabling young people who are currently in treatment to hear stories of recovery from people who have had an eating disorder but are now managing life without one. The peer relationship is a reciprocal and equal one provided as an adjunct to therapy. Peer workers facilitate groups for patients in the day, inpatient and outpatient programs. Carer Peers are family members of someone who had an eating disorder, that have been trained to support other families within PMH EDP.

Evaluation of this project has demonstrated that peer support can be an effective addition to treatment, drawing on the in-depth, lived experience knowledge and understanding of the eating disordered process and what it takes to recover. A well-trained peer support worker is like a 'recovery coach' for patients and can urge them to engage with their treatment, resist the distorted thoughts and provide a role model for life after the eating disorder.



Purcell, J., Lister, S., McCormack, J., Caswell, J. Logie, K. Wade, S. and Stringer, M. (2014). Reaching out for hope-a peer support program. *Journal of eating disorders*; 2(1): p. O63.

Peer Mentor Program – Eating Disorders Queensland

The EDQ Peer Mentor Program (PMP) aims to support individuals who are in recovery from an eating disorder living in the community through a lived experience peer model. This collaborative program addresses identified gaps for people recovering from eating issues in the areas of: social isolation, experiences of stigma, safe meal support environment, supported community recovery. The PMP provides a comprehensive recruitment and training program for peer mentors and volunteers. Training focusses on awareness of the mentoring role, boundaries, skills, risk management and self-care, developing social networks and becoming a non-professional buddy. Early evaluation results indicate that the program is effective in reducing social isolation, increasing hope and supporting connections.



Dearden, A. and Lee, A. (2014). Isis – Recovery Oriented Peer Mentor Program. *Journal of Eating Disorders*, 1 (Suppl 1): 5.

Carer Consultant – Victorian Centre of Excellence in Eating Disorders (CEED)

The Victorian Centre of Excellence in Eating Disorders (CEED) is a peak support organisation for the public mental health system providing a variety of services, generally falling under the three categories of service development, training and professional development, and secondary consultations, including the attendance at complex case conferences when necessary. A carer consultant has been employed over the last 4 years to enhance the CEED team's knowledge and

understanding of a carer perspective and improve service delivery by modelling the benefits of carer input to casework and service planning across Victoria.

The scope of the role includes co-development and delivery of training for clinicians and carers; co-development of resources for clinicians to provide families and carers; and participation in CEED team clinical case review meetings. In addition, the carer consultant has been available to provide consultations with families in service settings across the state in a single session framework. These consultations provide support for both families and generalist clinicians who all attend the sessions. It is apparent from feedback that having someone who is expert by experience as a part of the team adds significant value to the functioning of the team and enriches both training and consultation responses provided by CEED. The involvement of a carer in training and secondary consultation was identified by external clinicians as critical and was well received.



CEED Carer Consultation Service:

http://www.ceed.org.au/sites/default/files/resources/documents/Carer%20consultation%20process%20summary%20for%20services%20FINAL_1.pdf

International Programs

The following peer programs were reviewed based on published literature. No survey or personal interview information is included in the descriptions of these programs.

SHARED (Self-Help and Recovery guide for Eating Disorders)

The SHARED approach supplements treatment as usual for people with Anorexia Nervosa with a guided self-help intervention incorporating peer mentoring and a series of short videos that included personal narratives from people who had recovered from eating disorders. Peer mentors provided weekly, online, text-based guidance to enhance the participant's motivation and to complement the use of the self-care workbook. The peer mentors offered support using a secure platform for online chat for up to one hour a week for six weeks. The peer mentors had lived experience of eating disorders, were trained professionals in allied health, medicine, psychology, counselling, teaching or equivalent. People with clinical anxiety, depression or eating disorder symptoms were excluded. The peer mentors were provided with comprehensive training to support program delivery and trained in motivational interviewing.

The expected outcomes for participants were weight gain and improved eating disorder symptoms, mediated by improved motivation and confidence to change, compliance with treatment and improved social adjustment and mood. Cardi et. Al. [2015 and 2017] have reported on this randomised control trial but at the time of writing the outcomes were not available.



Cardi, V., Ambwani, S., Crosby R., et al. (2015). Self-Help and Recovery guide for Eating Disorders (SHARED): study protocol for a randomized controlled trial. *Trials*; 16:165.

<https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-015-0701-6>

ECHOMANTRA

ECHOMANTRA, Experienced Carers Helping Others, with patients engaging in the Maudsley Model of Anorexia Nervosa Treatment for Adults (MANTRA). This study provided carers with information to strengthen their coping with the caregiving role. The intervention was part of a randomised controlled trial with patients randomly allocated to treatment as usual (TAU) or TAU plus the intervention. For those in the intervention group, the support continued with the transition home following admission. The program offers carers guidance and support, it teaches skills such as positive communication and behaviour change, and includes videos produced by patients and carers showing adaptive and less adaptive support strategies. The videos are linked to a workbook and eight online moderated discussions. The patients were also provided with a workbook, video podcasts and online moderated group discussions. The patients and their carer connected with a carer mentor online for up to six sessions. Cardi et al. (2017) also reported on the design of this randomised control trial. The outcomes of the trial were not available at the time of writing.

Hypothesised outcomes for patients includes improved psychological wellbeing; improved body mass index (BMI); reduced eating disorder symptoms; improved work and social adjustment, quality of life and social functioning; and reduced days spent in hospital. Outcomes are assessed at 12 and 18 months. The expected carer outcomes are reduced psychological distress and time spent caring, and improved skills in dealing with eating disorder symptoms all at 12 and 18 months. At the time of writing the outcomes for this randomised control trial are not available (Cardi et al. 2017)



Cardi, V., et al. (2017). Transition Care in Anorexia Nervosa Through Guidance Online from Peer and Carer Expertise (TRIANGLE): study protocol for a randomised controlled trial. *European Eating Disorders Review*; 25(6): p. 512-523. <https://onlinelibrary.wiley.com/doi/abs/10.1002/erv.2542>

MentorCONNECT

MentorCONNECT was a program founded in 2009 by a person in recovery from an eating disorder. This program connected Mentors with Mentees to provide additional support for their recovery from an eating disorder. Mentors were volunteers who were mental health professionals that specialised in eating disorders or were individuals who had at least 12 consecutive months' sustained recovery from eating disorder thoughts and behaviours. Peer mentor volunteers were screened to assess their recovery status prior to work. Mentors documented a personal recovery history, why they wanted to work as a mentor, what they had to offer and their availability and preferred method of contact. This information was

posted on a password protected page for mentees to select their preferred mentor. Mentors provided a minimum of one hour of support per week to each mentee. The services were provided at no cost to the mentee. Once matched, the mentee and mentor decided on the mode and frequency of contact and how both parties would respectfully end the relationship if they need or want to discontinue. The timeframe for the mentoring relationship varied from a few months to a several years depending on the needs of the mentee. The program evaluation was reported by Perez, et. al. (2014).

The MentorCONNECT study compared matched mentees with unmatched mentees and looked at motivation, confidence and energy for recovery and quality of life. The mentees completed the Eating Disorder Quality of Life Scale and the Eating Disorder Diagnostic Scale, with the removal of the question for self-reported weight. Outcomes for matched mentees included higher levels of quality of life in education/vocation, family and close relationships, future outlook, psychological, emotional, values and beliefs and physical domains than unmatched mentees. Matched and unmatched mentees reported consistent levels of high eating disorder symptoms and overall psychiatric symptom severity. There was no difference between matched and unmatched mentees in motivation towards recovery, energy towards recovery and confidence that they will recover. Matched mentees reported missing significantly fewer treatment sessions. Mentors reported that the mentoring process positively impacted their own recovery process, including strengthening their skills and reminding them how far they have come in their own recovery. While the study reported positive benefits for both mentees and mentors, the program ceased operation in 2017.



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