An eating disorder-focused peer workforce: Needs assessment

**Research findings
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Butterfly
LET'S TALK eating disorders

Contents

1. Executive summary

Butterfly Foundation (Butterfly) commissioned Kantar Public to undertake research to explore the current landscape of peer work in the treatment and management of eating disorders to:

- Understand the full scope of eating disorder peer work ('ED peer work') currently being delivered in Australia
- Explore barriers to accessing ED peer work in the current climate
- Identify unmet needs and gaps in ED peer work service delivery, and
- Identify key requirements for expansion of ED peer work in Australia.

Specifically, this research explores the value offered by ED peer work and considers the conditions for how to optimise this workforce.

The research comprised two stages: a rapid literature review, followed by primary research in the form of 38 qualitative interviews with a range of key informants. The final sample included ED peer workers, people who have accessed ED peer worker support, clinicians who have worked with ED peer workers and/or had clients who have accessed this from of support, and sector organisations with experience in implementing an ED peer work model (in Australia and internationally).

The rapid literature review identified a range of benefits of ED peer work as an adjunct to clinical care. For the person participating in the peer work, these included increased empowerment, hope, greater acceptance and attendance at treatment and reduced feelings of isolation. It also outlined benefits for the peer worker, including aiding reflection and validation of their own recovery and experience, and upskilling. However, the existing evidence base is limited and relied on small pilot programs, with small sample sizes, no control groups, and limited timeframes. In addition, the literature does not adequately identify the factors that contribute to the development and implementation of a successful ED focused peer workforce. Lastly, little of the evidence was based on ED peer work programs conducted in Australia, and the evidence that did was based on pilot programs/approaches, limiting our understanding of the real-world context.

Primary research aimed to address some of the gaps highlighted in the literature review by exploring the current landscape of ED peer work practices in Australia (especially outside of pilot programs); deepening our understanding of perceived benefits and risks associated with ED peer work and how these manifest; identifying the factors limiting the potential of ED peer work in Australia; and exploring how to maximise the potential of ED peer work safely and effectively in the Australian context.

Overall, this research added to the growing consensus regarding the benefits of ED peer work, many of which reflected those identified in the literature review. For the person accessing ED peer work, these primarily centred around increased hope and reduced feelings of shame and stigma, contributing to increased engagement in treatment and a recovery mindset. Carer-to-carer support similarly offers increased hope, and an improved understanding of treatment approaches and relationships between clinicians and families. Ultimately, ED peer work offers those with lived experience a vital source of connection with someone who can truly empathise with their experience.

Potential risks of ED peer work for the peer worker, as well as the person accessing peer work, were identified. Concerns were raised about the potential for an ED peer worker to be triggered by the content of their interactions with a person experiencing an eating disorder, which in a worst-case scenario could result in relapse. It was widely agreed that, to reduce this risk, ED peer workers must be sufficiently recovered before trying to support others but there was a lack of consensus about how recovery should ideally be defined and assessed in this context. Participants also raised concerns about the potential for ED peer workers to become overloaded and 'burn out' if appropriate boundaries like frequency of contact were not maintained. It was agreed that both training and supervision are essential for helping to reduce these risks, but there was a high degree of variability in the duration/intensity of training provided and the frequency and quality of supervision.

The risks to people accessing ED peer work also included some issues that could likely be mitigated through appropriate training and supervision for ED peer workers, as well as increased regulation over service delivery. The example of ED peer workers sharing triggering details about their own experience or over-stepping the boundaries of their role and/or expertise by straying into therapy or inadvertently creating a dependent relationship was raised. Another concern was the impact of relapse on the person accessing peer work, given that the ED peer worker may be a source of hope and motivation. It's possible that improving the way in which the recovery criteria for ED peer workers is defined and assessed could reduce this risk.

Many participants advocated for the need to expand the Australian ED peer workforce, as an adjunct to clinical care, both in terms of increasing the number of ED peer workers available to meet demand and possibly extend access to the service offering. Expansion was also favoured to facilitate appropriate peer worker matches for people in particular situations, such as parents of adults with an eating disorder, siblings, or members of LGBTQIA+ communities, for example. In addition to this, there are some peer workers who would like increased involvement in the provision of peer work e.g., through formal qualifications, whilst others seek only training and supervision to deliver more infrequent and informal peer work. Hence there is a need to expand the ED peer workforce not only to increase resources available in absolute terms, but also to account for the full scope of types of peer work that could be offered and the needs of people who provide peer support.

However, there are a range of barriers to this expansion. At the core of this issue is that the existing infrastructure for ED peer work in Australia is severely limited and exists primarily at a jurisdictional level only. There is a need for centralisation of the service offering such that a single coordination body which oversees and regulates quality of care. This needs to be underpinned by a standardised practice framework like that which exists in all other aspects of healthcare which not only sets out best practice guidelines but also outlines a structure for how and when peer work should be provided.

For example, a consensus needs to be reached on what different types of peer work comprise, how involved the peer worker is in someone's care and hence how this is positioned in the broader care paradigm, and then how this is facilitated through recruitment, training, supervision, and remuneration, all of which will contribute to retention of the workforce. Whilst these issues limit the degree of possible expansion, they also limit quality of the current service offering and must be addressed. Underpinning all of this is a need for increased funding, following a clear policy direction to build an eating disorder-focused peer workforce.

A large part of what is lacking is a robust evidence base that supports the need for ED peer work and the value that will be offered through its expansion. In addition, an evidence base is required to inform on how best to deliver ED peer work to optimise recovery outcomes (and what those target indicators are). Together these can be leveraged to not only build awareness and advocacy around this service intervention across industry stakeholders, but also amongst clinicians and people with lived experience. Without this, progress will likely be somewhat hampered. It is recommended that this be a priority area of need, alongside the need for addressing gaps in the ED peer workforce infrastructure.

2. Introduction

2.1   Background and context

The National Survey of Mental Health and Wellbeing found that nearly one in two Australians experience a mental disorder over the course of their lifetime. Mental health and substance abuse accounted for 12% of the total burden of disease in Australia in 2015, the fourth highest (Australian Burden of Disease Study 2015; AIHW 2019c). Moreover, mental health strongly affects not only the person experiencing poor mental health, but also families and carers (Slade et al., 2009; WHO, 2013).

The Commonwealth Government's National Mental Health Workforce Strategy (2021-2031), informed by deep consultation with the sector, aims to support the effective provision of services across the mental health sector. As an emerging and increasingly valuable intervention, lived experience work has been identified as a priority area for mental health, with the National Mental Health Commission releasing the National Lived Experience (Peer) Workforce Guidelines in 2021 (Byrne, et. al., 2021). In addition to this, strategies, guidelines, and frameworks are in development or have been developed at a jurisdictional level in Queensland, Tasmania, Victoria, and Western Australia (Cleary, Thomas and Boyle, 2020). The lived experience workforce encompasses a range of roles including the provision of peer work, advocating for those with lived experience and for the value of peer work, and advisory or consultative opportunities.

Peer workers are distinguished from other healthcare professionals in that they have lived experience of mental health challenges, either personally or in support of someone close to them such as a family member. They work directly with people still experiencing mental health challenges to achieve recovery outcomes, as opposed to those with lived experience who perform advocacy or advisory roles. They are distinguished by the formalised nature of their role in the recovery journey and from informal peer work facilitated through social support networks (Slade et. al, 2014).

Peer work in mental health is therefore an increasingly important area in the management of mental health conditions, due to the benefits for clinical, subjective, and social outcomes (Slade et al. 2014). Furthermore, it is thought to be highly effective at promoting hope, empowerment, self-esteem, self-efficacy, social inclusion, and engagement (Repper and Carter, 2011) which are pivotal in improving recovery outcomes, and in the longer term, reducing the burden of disease.

As will be discussed in more detail later in this report, the initial evidence indicates that peer work has particular value in eating disorders. However, further work is required to better understand how to optimally deliver peer work services alongside established approaches to treatment and support.

In line with this need and with the National Strategy, Butterfly Foundation (Butterfly) commissioned Kantar Public to undertake research into the current landscape for peer work in eating disorders to:

• Understand the full scope of peer work being delivered
• Explore barriers to accessing peer work in the current climate
• Identify unmet needs and gaps in service delivery, and
• Identify key requirements for expansion.

The research comprised two stages: a literature review and second, primary research in the form of qualitative interviews with a range of key informants. This report represents the culmination of this research and will: provide an overview of the eating disorder landscape in Australia; outline key outcomes from the literature review; and discuss the primary research findings; before concluding with several considerations for expansion of the eating disorder peer workforce in Australia.

2.2   Eating disorders in Australia

Eating disorders are a group of serious and complex bio-psychosocial disorders that range in severity from moderately severe to critical and life threatening. The DSM-5 (American Psychiatric Association, 2013) specifies the spectrum of eating disorders to include Anorexia Nervosa, Avoidant/Restrictive Food Intake Disorder (ARFID), Binge-Eating Disorder, Bulimia Nervosa, Elimination Disorder, Other Specified Feeding or Eating Disorders (OSFED), Unspecified Feeding or Eating Disorders, Pica, and Rumination Disorder.

Eating disorders are estimated to affect between 4 and 16% of the Australian population (Australian Institute of Health and Welfare, 2018) which means more than one million Australians are living with eating disorders each year (Deloitte Access Economics, 2019; Butterfly Foundation, 2020). The evidence suggests the incidence of eating disorder symptoms and disordered eating is increasing (Hay et al., 2008); a trend exacerbated during the COVID-19 pandemic (Rogers et al., 2020), in turn reinforcing the need for a focus on eating disorders for mental health policy and service delivery.

The most common type of eating disorder in Australia is Binge Eating Disorder (47% of all diagnoses); followed by Bulimia Nervosa (12%) and then Anorexia Nervosa (3%) (Paxton et al., 2012). Prevalence is higher amongst women with 63% of people diagnosed with an eating disorder identifying as female (Paxton et al., 2012) and 15% of all women experiencing an eating disorder over their lifetime (Micali et.al., 2017), although it's likely that prevalence amongst males is underestimated due to under- or misdiagnosis (Butterfly Foundation, 2020). Eating disorders can occur at any stage of life but are most common during adolescence (Australian Institute of Health and Welfare, 2018).

The aetiology, presentation, treatment, ongoing management, and prevention of relapse of eating disorders is undeniably complex, with unique challenges to overcome. Anorexia Nervosa, for example, has the highest mortality rate of any mental illness (apart from substance use disorders) (Arcelus et al, 2011; Chesney et al, 2014). Comorbidity is common, with between 55 and 97% of people with an eating disorder experiencing comorbid mental illness including: depression, anxiety, personality disorders, and substance abuse (Hudson et al., 2007; NEDC, 2017). Treatment of eating disorders thus requires a delicate balance – and a holistic, integrated approach – to manage the range of symptoms people can experience and achieve recovery across (potentially) several indications.

A significant challenge in treating and managing eating disorders, however, is that people often don't seek help; the evidence suggests only 23% of people with eating disorder symptoms sought professional help over time (Hart et al., 2011). There are several barriers to help-seeking that have been identified including stigma and shame, denial of their disorder, not recognising how serious their illness is, treatments costs, lack of motivation for recovery, limited encouragement for recovery, and lack of awareness of the different help-seeking options available (Ali et. al., 2016). Accordingly, Ali et. al., (2016) recommend treatment interventions that focus on overcoming these barriers, which is where peer workers are well positioned to help given their unique ability to support feelings of hope, empowerment, building self-esteem, and so forth.

Moreover, it is estimated that only 50-74% of people experiencing an eating disorder achieve a full recovery (Fairweather-Schmidt and Wade, 2014) with the average time taken to recover from all types of eating disorders ranging from 1-6 years (Deloitte Access Economics, 2015). Premature dropout from treatment also presents a risk with between 20% and 51% of inpatients, and 29% and 73% of outpatients, discontinuing treatment (Fassino et al., 2009). A recent longitudinal study found recovery rates of 31.4% at 9-year follow up, progressing to 62.8% at 22 years (Eddy, et. al, 2017) but 25% of individuals suffer from a severe and long-term illness (Deloitte Access Economics, 2015). Finally, recurrence of illness is common with relapse rates estimated to be 22% - 60% (Troyer, 2014).

Sustained recovery is possible, however. It is more likely if a person has continued access to support once in remission, to promote wellbeing and early help seeking should it be required; and is also more likely if someone seeks help earlier in the illness (Butterfly Foundation 2017). This means it is important to invest in ensuring continued access to treatment interventions beyond the acute phase of illness, through the transitional phase, and whilst in recovery.

Notwithstanding the psychological burden that comes with suffering from an eating disorder, eating disorders also present a significant socio-economic cost to Australia, with Deloitte Access Economics (2015) estimating the burden of disease to be $53.7 billion, or $20,970 per person. Effective and early interventions are thus not only critical for improving sustained treatment outcomes but also for reducing the economic and social burden of eating disorders.

2.3   Treatment of eating disorders

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) provides a set of general principles and guidelines for treatment that focus on person-centred care which looks beyond the illness toward the individual's broader life context and needs (Hay et al., 2014). Best practice guidelines promote a recovery-oriented, long-term, and multi-disciplinary approach that integrates medical, nutritional, and psychological treatment in a stepped, seamless care model, within a supportive environment (Hay et al., 2014).

The National Eating Disorders Collaboration (NEDC, 2019) developed the first national Australian framework for the treatment and management of eating disorders in 2012. This describes seven core principles for treating eating disorders and four implementation principles. These provide the foundation for an effective and nationally consistent system for treating and managing eating disorders in Australia. The practice principles are:

1. Person and family centred care that addresses the needs of individuals
2. Prioritisation of prevention, early identification, and early intervention
3. Safety and flexibility in treatment options
4. Partnering to deliver multi-disciplinary treatment in a continuum of care
5. Equity of access and entry
6. Tertiary consultation accessible at all levels of treatment
7. Support for families and carers as integral members of the team.

These principles ultimately describe the most effective treatment approach as being individually tailored, collaborative and flexible, taking a holistic approach and with a core contextual focus on the person experiencing an eating disorder, their family/carer/s, and their environment. They also reflect a continuum of care, where individual and family/carer needs are addressed across prevention, treatment, and support services – not only those of the sufferer.

More recently, recommendations from the Australia and New Zealand Academy for Eating Disorders (ANZAED) (Heruc et. al., 2020) determined no single service model for the treatment of eating disorders could or should be specified, but several principles guide the development and implementation of service delivery. These are that:

1. Early intervention is essential
2. Co-ordination of services is fundamental to all service model
3. Services must be evidence-based
4. Involvement of significant others in service provision is highly desirable
5. Personalised treatment approach is required for all people experiencing an eating disorder
6. Education and/or psychoeducation is included in all interventions
7. Multidisciplinary care is required
8. A skilled workforce is necessary.

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[1] Burden of disease is calculated by multiplying the years of healthy life lost (measured in disability adjusted life years or DALYS), by the value of a statistical life year (VSLY) as recommended by the Department of Finance and Deregulation (Paxton et al., 2012).

Both the NEDC National Framework and the ANZAED recommendations emphasise well-coordinated and multidisciplinary treatment that incorporates the affected individual, their family and significant others. Furthermore, the focus is on both the immediate clinical concerns as well as longer-term support to enable meaningful quality of life and a sustainable recovery. As will be described later in this report, peer work has value in the latter regard.

Treatment of eating disorders makes use of a range of psychological therapies (Butterfly Foundation, 2017) including Maudsley Family Based Therapy (FBT) for adolescents, Cognitive Behavioural Therapy (CBT) for adults, Specialist Supportive Clinical Management (SSCM) for adults, and nutritional interventions amongst individuals experiencing Anorexia Nervosa. Cognitive Behavioural Therapy, Interpersonal psychotherapy, and nutritional interventions are recommended amongst Bulimia Nervosa and Binge Eating Disorder. It is important to highlight, however, that these therapies often lack focus on the broader context of the individual and their integration in social and community settings, as well as their identity and values beyond the disorder itself (Lewis and Foye, 2021). Such gaps in clinical interventions could be addressed through complementary therapy approaches like that offered through peer work.

Peer work provides a person-centred and personalised approach that also accounts for families and carers, in alignment with the NEDC National Framework and the ANZAED principles of practice. The initial evidence suggests peer workers are critical in supporting and helping a person experiencing an eating disorder to achieve recovery due to their lived experience (Beveridge et al. 2018). Early pilot studies and randomised control trials have shown promising results for both clinical and non-clinical outcomes (e.g., increased self-esteem, social connection, motivation). Reciprocal benefits also have been identified for both the person experiencing an eating disorder and the peer worker themselves (Fogarty, Ramjan and Hay, 2016). Despite these early positive findings, the role of peer work in eating disorder service settings (particularly in Australia) is understudied and warrants further attention.

2.4   Making the case for a lived experience workforce

Focusing attention on the expansion and implementation of an eating-disorder focused peer workforce is both timely and in alignment with current mental health policy directions. As mentioned previously, the Commonwealth Government established the National Mental Health Workforce Strategy Taskforce to assess the quality, supply, distribution, and structure of the mental health workforce. A particular focus is on the role of peer work.

The Commonwealth Government has also recently released the country's first National Eating Disorder Research and Translation Strategy 2021-31, which identifies 10 priority areas for research into eating disorders over the next ten years (Department of Health, 2021). These priorities include prevention, risk and protective factors, early identification, equity of access, treatment outcomes, individualised medicine, family support, early intervention, positive and negative treatment impacts, stigma, and health promotion – all of which can be supported through the provision of peer work.

The additional context of the COVID-19 pandemic has increased prevalence of eating disorders and eating disorder symptomology (McLean, Utpala and Sharp, 2021), in line with declining mental health more broadly across the population (Lin et al., 2021). Additionally, the rise of social media and web-based applications have increased accessibility to pro-eating disorder communities that promote eating disorder behaviours and shun recovery (Sowles et al., 2018). While some online forums can offer a positive opportunity for people with lived experience of eating disorders to support others through recovery (LaMarre and Rice, 2017), others direct people to pro-eating disorder websites and forums (Sowles et al. 2018). Access to peer workers could therefore help moderate the influence of harmful online communities through the benefit of lived experience, and specifically facilitate formalised, recovery-orientated, help-seeking rather than social and relational recovery support.

Recognising the potential place for peer work specifically in eating disorder treatment, the NEDC released its Peer Work Guide in 2019 – the goal of which was to provide a foundational guide for developing an eating disorder-focused peer workforce. This work was informed by a review of the eating disorder-related peer workforce in Australia at the time, much of which was informal and unregulated. The NEDC review identified several gaps, barriers and unmet needs that exist within the current peer workforce, but also provided strong evidence for its place in boosting efficacy of the current treatment model.

What this review did not do – largely because this simply wasn't available in the context – is provide evidence that links the impact of specific parts of the workforce model such as recruitment, to performance indicators like improved eating disorder symptomology, to guide exactly how the peer workforce should be expanded and maintained. Moreover, there is currently a lack of insight from – and formal evaluation of – real world experience at a global level.

More recently, the National Mental Health Commission released their National Lived Experience Development Guidelines. The Guidelines were developed with expansive consultation with individuals with indirect or personal lived experience of eating disorders, families/carers, peer workers, government department employees, mental health commissions, managers/employers, and non-designated colleagues. Although a large total sample, only three people with experience of eating disorders were consulted meaning specific insights in this area were limited.

These Guidelines specify that peer work must reflect shared values. More precisely, peer work must facilitate an environment in which the 'power' between the person with lived experience and others – for example, clinicians – is shared, and the power difference is reduced. Additionally, the Guidelines specify that peer work must be built on a foundation of respect, hope and belief in the inherent capacity of the other, and meeting people where they are at in a non-judgmental manner (amongst others).

The Guidelines support the positioning of peer work as distinct from traditional service delivery, with a focus on connection, informed by personal and collective lived experience and expertise, over clinical outcomes. The Guidelines further outline a strengths-based practice framework for peer work which advocates for recovery/recovery-orientated practice, community development, and being trauma-informed. Moreover, the frameworks recommend a non-clinical approach to peer work that accounts for broader mental and emotional wellbeing, with scope for systems change, and which is governed by a defined coaching framework.

It is also recommended (note this is not the exhaustive list) that:

- National and state peak bodies are required for peer workers that are separate to existing consumer and carer peak bodies
- More lived experience-led/run organisations are needed, as well as an advocacy body for peer workers including education of existing unions regarding the unique needs of peer workers
- Clear workplace standards and mechanisms to hold organisations to account are implemented as well as consistent values and principles underpinning peer work at national and jurisdictional levels
- Pathways for professional development and leadership amongst peer workers should be possible and facilitated
- Best practice examples, templates, resources
- Fair and adequate renumeration for the peer workforce.

In the context of such research and the consultation already having been completed, a key aim of this research project is to address some of the existing knowledge gaps and extend the knowledge base from a larger sample than was included in the NEDC and NMHC consultations. By engaging with those who have real world experience with eating disorder peer work it is possible to deepen our understanding of eating disorder peer work in Australia and gather guidance around what works, and what doesn't. An additional aim is to gain global insight via consultation with international stakeholders.

There are indications that a peer workforce to support treatment and management of eating disorders would yield significant outcomes. It is imperative that we understand – and action – how to design and implement an effective and safe eating disorder peer workforce in Australia.

2.5 Research areas

Underpinning this research are four overarching themes and research questions. These are:

1. **Benefits:** what are the key benefits of establishing and integrating an eating disorder-focused peer workforce in Australia?

2. **Operationalisation:** what is the pathway for operationalising this need, from development to implementation?

3. **Success factors:** what are the key factors influencing success of the peer work model?

4. **Safety considerations:** how to properly safeguard peer workers and the people they support?

The insights discussed in the main body of this work reveal that often, there is significant overlap between each of these elements and to a large extent, these interact with each other. For example, a key benefit of peer work is the provision of hope which contributes to the success of peer work but can also pose a risk to either the peer worker or the person they're supporting should that hope be lost. As such, the research outcomes are integrated throughout the report rather than organised as above.

2.6 Overview of approach

Two phases of research were conducted. An overview of the methodology for the literature can be found in Section 3.2, whilst detailed methodology for the informant interviews can be found in Section 4. In brief, these included:

1. Rapid literature review

   a. The objective of the rapid literature review was to examine the existing literature regarding lived experience work in eating disorders, in Australia and at a global level, to first identify if a consensus exists regarding best practice guidelines or framework and second, to leverage program evaluations and peer-reviewed researching including RCTs to identify success factors and appropriate outcome indicators.

2. Key informant interviews

   a. 60-minute in-depth interviews with individuals who have experience of accessing, providing, and facilitating lived experience work as well as industry stakeholders and advocates, in Australia and globally.

This structure enabled an iterative approach to the research such that the literature review informed the structure and content for key informant interviews, and both components of this research were continuously refined as the project progressed and insights generated.

2.7 Glossary of terms

This research has identified a lack of clarity around some of the terminology used in relation to ED peer work, and this is an area requiring further investigation. However, for the purposes of this report, the following definitions have been used.

Clinician – a health professional qualified in the clinical practice of medicine, psychiatry, or psychology.

Group sessions – a form of peer work attended by multiple participants with lived experience of an eating disorder, or their carers/families, facilitated by a peer worker, sometimes in conjunction with another peer worker or clinician.

One-to-one mentoring – a form of goal-orientated peer work provided to those with direct lived experience of an eating disorder (as opposed to family members), often intended to support people with an eating disorder as they transition back into community settings. Typically delivered over a fixed term, with clearly stipulated frequency of contact. Most strongly associated with peer work delivered through state-based organisations.

One-to-one coaching – a form of peer work delivered by independent peer workers, typically by those who have completed the Carolyn Costin training. A broader form of peer work, including, for example, helping clients to deal with intrusive eating disorder thoughts, crisis management and in the moment support outside of scheduled session and office hours.

Peer work – support provided to a person currently affected by an eating disorder (directly or as a carer), by a person who has had lived experience of an eating disorder, or of caring for someone with an eating disorder.

Residential/hospital-based peer work – a form of peer work provided within individual hospitals or centres for inpatients, where peer workers are asked to undertake a range of activities, which may include meal support. This type of peer work appears to be the most ad hoc, with significant variation between health services.

Stakeholder – an individual or organisation with an interest in policy and practice relating to eating disorder peer work.

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[2] It is noted that non-person-facing ED peer work, such as consultancy or advocacy roles, were out of scope for this study. Also, the NMHC National Lived Experience Guidelines use the term 'lived experience' throughout to refer to all types of peer work. Although this was not an area for deeper exploration in this study, it was found that existing lived experience programs explicitly reference 'peer work' and few participants expressed objections to this, hence the term 'peer work' is used throughout this report.

3. Rapid literature review – summary

3.1 Introduction

As noted in Section 1, in 2019, the National Eating Disorders Collaboration (NEDC) commissioned a literature review and consultation with an expert advisory panel. The outcome of this was a guide to inform the development of an eating disorder peer workforce, the NEDC Peer Work Guide, which provides a foundation for our understanding of the requirements for a lived experience workforce in this area. However, some gaps in knowledge still exist. Accordingly, the overarching objective for the research completed by Kantar Public has been to delve more deeply into some of these knowledge gaps (note this section is a summary only; the full literature review is available on request to Butterfly).

To that end, a rapid review of the literature regarding best practice for a peer workforce in the treatment and management of eating disorders was conducted between 14 October and 10 November 2021, in close collaboration with the Butterfly project team. This review sought to identify new inputs, specifically around eating disorder-focused peer work models globally, including international benchmarks, to avoid repetition of the work conducted by the NEDC. And secondly, it aimed to develop hypotheses about how and why the knowledge gaps may exist to guide the primary research (in-depth interviews with a broad range of stakeholders including current peer workers).

Note - as indicated in the Glossary of terms, 'peer work' is used throughout this report to refer to support provided to a person currently affected by an eating disorder, by a person who has had lived experience of an eating disorder, or of caring for someone with an eating disorder.

Documents included in this review were assessed for their relevance to the topic and included:

- Policy documents at a national and jurisdictional level
- Systematic and meta-analytic reviews, and discussion papers
- Grey literature and academic peer-reviewed literature on eating disorder-focused peer workforces including pilot programs.

A practical, rather than theoretical, lens was applied on the assumption that this would better facilitate the identification of exactly what value a peer workforce has for eating disorders – and how to implement this safely and effectively. Accordingly, the literature review was structured to answer eight key questions:

1. What are the key benefits of an eating disorder-focused peer workforce and how should we articulate these?

2. How might a peer workforce benefit those beyond the person living with eating disorder?

3. What is the best approach for formalising the role of the peer worker within the existing treatment model and multidisciplinary team (MDT)?

4. How should the peer workforce be structured and what is the optimal level of involvement for the peer worker?

5. Should the peer workforce be volunteer-based or an employment opportunity?

6. How should peer workers be recruited to maximise supply, retention, and mitigate risk?

7. What training and supervision is required to optimise service delivery, support positive mental health, and minimise risk for the peer worker, as well as the person experiencing an eating disorder?

8. What is the optimal relationship dynamic between a peer worker and the person experiencing an eating disorder and/or family/carer of a person experiencing an eating disorder, and how can this be facilitated?

Overlaying this was an investigation of whether eating disorder peer work has unique risks and challenges that need to be explicitly addressed in existing peer work frameworks and/or that may require a separate approach.

3.2   Methodology

A tightly defined and targeted rapid literature review was undertaken prior to the completion of primary research, with a focus on meta-analyses and systematic reviews, as well as available evaluations of relevant peer work programs and grey literature.

'Open searches' were conducted using various databases with content in a wide-range of relevant areas, including ProQuest Central, OVID Medline, PubMed, AMED (Allied and Complementary Medicine), PsycARTICLES, Google scholar, and a Google search for grey literature.

3.2.1   Key words

The following key words and search terms related to programs about lived experience work and eating disorder prevention and/or treatment, including combinations, were used: 'eating disorder', 'body image', 'peer work', 'peer workforce',' support programs', 'peer support', 'coaching', 'peer mentor', 'peer coach', 'recovery coach', 'peer worker', 'mentor training', 'mentor guidance', 'care navigators', 'group facilitators'.

3.2.2   Inclusion criteria

Inclusion criteria included reports on eating disorder treatment or prevention involving peer workers or peer mentors, available in English and published in Australia or internationally in the UK, New Zealand, Canada, USA, or The Netherlands, published in 2010 or later.

Anecdotal or new primary evidence e.g., in relation to existing peer work that has not been published or peer-reviewed for efficacy was not included because this was the focus of the primary qualitative research. Participants in the primary research (detailed in this report) were asked to direct the research team to relevant evaluations or publications not already identified via open searches, to ensure completeness.

Research and evaluation documents were assessed for relevance and utility before being read in detail (via abstracts, executive summaries etc.), allowing us to prioritise the reading and analysis of documents. Contents, reference lists, and bibliographic indices in relevant sources were also followed up at this stage. Seven of the pilots / programs covered by the identified literature were conducted in Australia and ten were conducted or based overseas – however, none were identified as best practice examples.

Several other papers are referenced that are not evaluations of individual programs/pilots in specific jurisdictions, but still provide relevant information (e.g., literature reviews, papers reporting on perspectives provided by peer workers or other stakeholders).

3.3   Key findings

This section summarises the key findings from the rapid literature review.

The review ultimately revealed that, to date, there has been insufficient research into the best way to develop and implement an eating disorder-focused peer workforce. While the NEDC Peer Work Guide provides guidance, a systematic and practical framework for developing and implementing an eating disorder-focused peer workforce in Australia is not currently available.

In addition to there being relatively few published studies into peer work in the eating disorder field, many of the studies that are available focus on pilot programs, the robustness of which are often restricted by short timeframes and small sample sizes. These pilot programs cannot, therefore, discuss the potential long-term effects of peer work for both people living with an eating disorder and the peer worker with much degree of confidence, which is critical when designing an appropriate peer workforce model for people with eating disorders.

The existing evidence also tends to focus more on the outcomes for the individual participant in their treatment and recovery journey and less on the outcomes for the peer worker themselves, where we believe significant risk may lie, such that the peer worker becomes at increased risk of relapse. This is likely to be a risk that is unique to peer work in the eating disorder space compared with other mental health disorders. Moreover, the literature does not adequately discuss the processes and structures that enable a positive working environment, and safe and sustainable employment model for peer workers. Specifically, while brief mention is given to issues surrounding training, supervision, and remuneration, the focus is more on measuring outcomes of the peer work intervention rather than the various structural factors or processes that contribute to the success or failure of a particular pilot or program in detail.

Finally, only seven of the available research papers were based on programs conducted in Australia, and all of these were pilot programs/approaches. This means there is limited understanding of current practice and challenges in the Australian context, particularly outside of pilot programs.

3.4   Conclusions and implications

The literature review demonstrated that there is broad agreement regarding the value of peer work in the treatment and management of mental health, and it is a priority area at a national level for the forthcoming National Mental Health Workforce Strategy (2021-2031). However, it also demonstrated that much of what is known or discussed regarding eating disorders is anecdotal with only a limited amount of academic or grey literature directly demonstrating the positive impact on clinical outcomes. This is not surprising and nor is it particularly concerning because ultimately, the introduction of peer work is in its infancy in Australia, and this is particularly the case for eating disorder peer work. Accordingly, in the primary research, we sought interviews with internationally placed stakeholders who have experience with implementing an eating disorder-focused peer work model to critically examine the benefits they have observed, and the factors which influence success.

The existing literature discusses benefits of peer work for the individual affected by an eating disorder like increased empowerment and optimism in the recovery journey, greater acceptance and attendance of treatment, and reduced feelings of social isolation. From the perspective of the peer worker, increased levels of self-awareness which aide positive personal recovery reflections, validation, and various forms of upskilling are reported as benefits. It is important to be note that these benefits relate to both the individual who is experiencing an eating disorder thereby accessing peer support, and the peer worker themselves hence there appears to be a dual benefit to this type of intervention. A hypothesis for the primary research was therefore that involvement in peer work could further solidify the peer workers' recovery thereby having clinical benefits that go beyond the person accessing peer work.

Another perspective is that peer work helps to address gaps in clinical treatment for people experiencing an eating disorder, particularly in terms of establishing a social and relational identity outside of the disorder, improving hope and navigating the pathway out of intensive clinical treatment. The literature posits that peer work has potential as an adjunct to other forms of treatment, including psychological and nutritional, within an MDT approach. Accordingly, this indicates that the expansion of existing peer work in Australia could have wide ramifications, including for the impact of managing and treating eating disorders on the health system.

However, the literature review identified several gaps in existing knowledge that must be addressed. Firstly, much of the literature relies on small pilot programs with limited sample size which limits their robustness and applicability to real world situations. Often these had no control group making it hard to discern the true impact of peer work, together with a lack of clinical evaluation, and limited timeframes. In addition, there is a lack of evidence pertaining to the policy and practice being used currently in peer worker programs in Australia, outside of the relatively small number described in published literature. For the peer workforce to be valued and improved in the longer term, these limitations must be addressed.

Furthermore, some of the evidence is conflicting – particularly regarding the safety of peer work for recovered individuals and the potential for relapse. It is possible that this arises due to limitations in study design, for example, different durations for the intervention and no standardisation of the recruitment and assessment criteria for the peer worker to determine if they are suitable to undertake the role. Moreover, there is a lack of consistency around the type of peer work that is being offered, which may also explain why some peer workers showed signs of relapse and others didn't. Understanding precisely what the optimal type of peer work is, and the ideal investment required of the peer worker to maximise clinical outcomes, whilst also maintaining their own mental health and wellbeing, should be a critical focus for future inquiry.

There is also a lack of evidence on the relationship between peer workers and other clinicians, with only some recent studies addressing the integration of peer workers into the broader multidisciplinary team. Further investigation is necessary to understand if peer workers should be integrated, and then how to structure a multidisciplinary treatment team that includes the peer worker, to ensure the most effective treatment outcomes for the individual experiencing an eating disorder, their family and support network.

Ultimately, what the review found is that the existing literature base is not sufficient to provide robust clarity on the benefits of peer work, such that peer work could be formally integrated into eating disorder treatment in Australia.

Note, it does indicate these benefits exist, but a secondary phase of research is needed to gain a greater degree of confidence in how a case could be made for the introduction of an eating-disorder specific model as a priority area for investment under the National Mental Health Workforce Strategy.

Additionally, the literature is too sparse and inconsistent to suggest the pathway to development and implementation in Australia, nor to have indications on the parameters for the model. For example, there does not appear to be a consensus on how the model should be structured nor what type of peer work (or types) should be offered, or how the peer worker role should be positioned to best engage clinical and peer stakeholders. Again, there are some indications and hypotheses, however the primary research sought to directly explore these issues with those who have experience of implementing a peer model and who would be involved in delivering care.

4. Key informant interviews methodology

To address the core research objectives, qualitative research was undertaken in the form of key informant interviews with eating disorder peer workers, people who have accessed eating disorder peer work, industry advocates, academics and facilitators of peer work, and Clinical Psychologists involved in the treatment and care of individuals with an eating disorder.

Participants were invited to undertake a 60-minute semi-structured interview, either via video teleconference (Microsoft Teams or Zoom) or telephone. Four semi-structured discussion guides (see Appendix) were developed in consultation with Butterfly, tailored to participant type. Participants gave informed consent and were fully debriefed on completion of the interview.

Fieldwork was completed between 25 November 2021 and 13 January 2022.

4.1   Recruitment

The sample was recruited via non-probability sampling, with the participant pool provided by Butterfly Foundation, as well as snowball sampling from participant recommendations.

Industry advocates, academics, and facilitators of peer work, as well as Clinical Psychologists involved in the treatment of eating disorders were first approached by Butterfly Foundation and invited to participate. Upon indicating their interest and with consent to share contact details with Kantar Public, interviews were subsequently scheduled at a time convenient to them. Some stakeholders assisted in snowball sampling by making referrals for additional participants who were first assessed by their suitability before contact was made – with their consent. Peer workers, and individuals who have accessed or participated in peer work, were recruited via the Butterfly Foundation database, and after this using snowball sampling.

Although Butterfly provided the sample, participation was on the condition of anonymity and that contributions are confidential, in accordance with Australian Privacy Laws and the Research Society's Code of Professional Behaviour.

4.2   Reimbursement

Peer workers or individuals who had accessed or participated in peer work were reimbursed for their participation by Butterfly, upon completion of the interview. Note that participants were not recruited with this financial incentive in mind; rather participation was intrinsically motivated.

4.3   Exclusion criteria

To safeguard participant wellbeing, participants with lived experience were excluded if they self-reported as having been an inpatient, or receiving residential treatment, in the past 12 months. Participants were not recruited into the study if they did not meet this definition.

4.4   Sample

A total of 38 people were recruited and participated in the qualitative research (Table 1). Sample breakdown and sub-group targets were agreed in collaboration with Butterfly Foundation; these were adjusted as fieldwork progressed to allow for flexibility and the availability of participants across each category. Participants were recruited from across Australia (NSW, Qld, Vic, Tas) and, in the case of industry stakeholders, internationally, and included:

- **Peer workers**
  - Individuals with lived experience of an eating disorder
  - Individuals who were carers or family members of a person who experienced an eating disorder
- **Persons accessing peer work**
  - Individuals with lived experience of an eating disorder
  - Families and carers for an individual who experienced an eating disorder
- **Industry stakeholders**
  - Advocates and facilitators of peer work in Australia
  - Advocates and facilitators of peer work in the United States, Canada, and the Netherlands
- **Clinicians currently treating eating disorders**
  - Both with an awareness and experience of peer work and those without

Note: Some participants had experience across multiple roles, including, for example, peer workers who had previously accessed peer support.

Table 1. Final sample

Stakeholder type	Participants (n)	Sampling procedure
Peer worker, lived experience of an eating disorder - Recovery coach - Peer mentor - Group facilitator - Miscellaneous	**11** 3 6 1 1	Mixed
Peer worker, family / carer experience of an eating disorder	**2**	Snowball
Recipients of peer work - Lived experience of an eating disorder - Family / carer experience of an eating disorder	**7** 6 1	Mixed
Clinicians	5	Snowball
Academics	2	Provided
Industry stakeholders – Australia	5	Provided
Industry stakeholders – International	6	Mixed
Total	**38**	

4.5   Interpreting the findings

The purpose of qualitative research such as this is to provide an in-depth understanding of participants' experiences, perceptions, and perspectives. Qualitative sample sizes are generally relatively small; to achieve a deep understanding, the amount of time spent with each participant is more important than the number of people consulted. However, this also means that the findings may not be representative of all stakeholders in the eating disorder space.

5. Key informant interviews findings

The outcomes of this research are, for the most part, aligned with the outcomes and recommendations discussed in the NMHC Lived Experience Workforce Development Guidelines. Strategically, therefore, the expansion of peer work in eating disorders should align with an overarching mental health peer workforce framework, for efficiency of process, regulation and quality of service delivery, and optimisation of outcomes.

What this research has revealed is that there is a hierarchy of importance to what is required for the expansion of an eating disorder peer workforce, as an adjunct to clinical care. Specifically, there are top-down contextual factors that currently restrict the potential for the peer workforce in eating disorders such as a lack of policy direction, public funding, centralisation of care and regulation, and a practice framework. Unless addressed first, these contextual factors will continue to undermine its potential and mean that factors at the level of service delivery also cannot be addressed due to e.g., lack of funding. This is perhaps best summarised below.

'Peer work is emerging in eating disorders... there's a lack of understanding about peer work though and I question if organisations are really ready to take on the roles...there's no clarity or framework but there is interest...generally people want it to happen and some are being proactive, but they're not clear what they want or how to do it.'

Industry stakeholder – Australia (paraphrased)

These findings are therefore structured to discuss these top-down contextual influences on the workforce before evaluating how well the current eating disorder peer workforce is positioned (i.e., how and when peer work should be accessed) against the current treatment model. A core focus for this section is then to explore unmet needs at the level of service delivery (such as variation in training, issues with recruitment) that currently exist, and which could be improved with e.g., increased funding.

First, however, the current landscape regarding eating disorder peer work in Australia is presented i.e., what types of peer work are currently offered and how these are accessed, together with anecdotal evidence regarding perceived and experienced benefits.

5.1   Peer work currently available to people with an eating disorder in Australia

This section will describe the spectrum of peer work currently available in Australia to people experiencing an eating disorder as was described during in-depth interviews, before evaluating if this scope of this work is effectively aligned with traditional service delivery and care models in a later section.

The lived experience workforce in eating disorders has been described as encompassing advocacy, coaching, and peer work. This is in accordance with the National Lived Experience Workforce Development Guidelines, prepared by the NMHC following consultation, in which participants report that lived experience work includes policy, strategic and non-human faces roles as well as 'human-facing' ones. Ultimately, these Guidelines propose that lived experience work is, at its core, non-clinical and 'orientated or informed by personal and collective lived experience or expertise'.

It is important to reference the broader remit of the lived experience workforce for the very fact that this research focused specifically on the 'human-facing' roles i.e., wherein the person with an eating disorder or a family member of someone with an eating disorder, has a direct relationship with someone with lived experience, referred to as peer work. The rationale for this approach was simply that peer work is felt to be the area of the greatest immediate need, for reasons such as demand outweighing supply, and the potential risks to the emotional well-being of someone offering peer work without proper regulation. Hence, further work is needed to explore the requirements for other types of lived experience work.

Currently, there are four main areas of 'human-facing' peer work within the eating disorder space. These are group sessions, one-to-one mentoring, one-to-one coaching, and residential. Broadly speaking, the first two tend to be delivered through outpatient or community care whilst coaching can occur in both inpatient and outpatient settings, and residential encompasses inpatient support, mentoring and coaching.

The terminology used to describe these areas reflect the language used by participants and will require deeper consideration. It is likely that an appropriate approach to formalising and standardising the delivery of care will be to delineate peer work by the level of involvement the supporter has in a person's recovery, and in which service delivery setting. What is clear though is that several types of peer work exist, all of which are variations on the theme of being recovery orientated and focused on connection and empathy.

The contractual arrangements for eating disorder peer workers in Australia include permanent full or part-time paid roles and paid casual roles, as well as voluntary roles (unpaid).

Group sessions

People with eating disorders can attend group meetings that are facilitated by someone with lived experience. These appear relatively common, however there is some degree of variety in the way they are delivered and a fair degree of inherent risk. It is worth noting that the recruitment undertaken in this research was skewed towards one-on-one peer work so conversation around group settings is possibly underrepresented and not fully representative of the spectrum on offer.

It was clear though that the group forum has the potential to effectively deliver peer work, and to a higher number of people than an exclusively one-on-one format; therefore, this approach could represent a positive return on investment going forward. State organisations offer group peer work either on an ongoing basis or as a fixed term program. In the case of the former, the structure of these sessions is less well defined and more flexible to accommodate the attendees needs that day, meaning this approach doesn't necessarily focus on an individual's treatment goals or the actions of their care team. For the latter, the structure is tailored to the timeframe with a different topic or focus for each session and 'homework' to be completed between sessions.

There are additional benefits to this type of peer work compared with one-to-one, reported mainly by those who have accessed peer work, indicating that these have distinct value. For example, group attendees report welcoming connection with others in similar situations to themselves and that this contributes to reducing feelings of isolation alongside appreciating the opportunity to be exposed to a range of coping strategies as shared by their peers.

On the other hand, clinicians and industry stakeholders are more cautious and discuss the heightened risks associated with group sessions, especially regarding anorexia nervosa. They spoke about the risk of an individual in a more acute state of illness with more prominent eating disorder thoughts and behaviours triggering others to negatively impact their recovery. Similarly, as reported by participants, the nature of e.g., anorexia nervosa is thought to pose a risk because attendees can be negatively triggered by the appearance of others. Although, it is also worth noting that this is also true of group therapy facilitated by someone without lived experience reflecting more the problem with group therapy than peer work itself.

As a result, there is the suggestion that group sessions should only be accessed when someone is in a recovery mindset – i.e., they want and are actively pursuing recovery, and are relatively well progressed on this path such that they possess a degree of resilience to potentially triggering situations. It will be important to consider and arrive at a consensus for how to define the appropriate threshold for recovery for someone to attend the group and mitigate the risk for negative impacts. This will be discussed in more detail later.

An alternative form of group peer work is that offered to the family members of someone experiencing an eating disorder. These appear to be the most common type of family peer work because the premise and basic need here is not recovery orientated. For them, the need is to seek solace in the comfort of others around a situation that is emotionally challenging, to feel hope engendered by the success stories of others and gain insight into the rationale behind treatment decisions or why certain behaviours may be occurring. They also seek to understand how they can help mitigate these behaviours.

One-to-one mentoring

The term 'mentoring' was most strongly associated with peer work delivered through state-based organisations meaning it also appears to be the most tightly regulated. In this research, it was the most common type of peer work encountered however this is likely to be somewhat skewed by the fact that recruitment was based on approaching programs and stakeholders known to Butterfly Foundation. Moreover, this mentoring style of work is specific to those with direct lived experience of an eating disorder as opposed to family experience (i.e., carer).

The term mentoring seems to be applied because the overarching aim is to provide goal-orientated support akin to other types of mentoring – i.e., there is a clear outcome the peer worker is mentoring someone towards achieving. It is currently available mainly through state-based not-for-profit eating disorder organisations to someone who is relatively progressed on their path to recovery but who is seeking support to complete activities like eating socially or in public or going shopping for clothes. Essentially, they are being supported to undertake activities that previously would have been avoided or were particularly triggering, but which are everyday activities for most people without an eating disorder.

> *"What it allows us to do is work within that grey space of healthcare where your dietitian or psychologist might be like, oh you need to try X, or we need to increase variety...and as a peer mentor we can provide / facilitate that in a safe way...You pick up with your own lived experience worker, who can understand how, [for example], social eating or changing what you're eating for lunch can be really confronting...so it's about sharing that space with them and providing wisdom or comfort, practice those skills and transfer them to their own lives."*
>
> Peer worker, lived experience of an eating disorder

This type of peer work is typically for a fixed duration of time, for example 12 weeks or 6 months with a clearly stipulated frequency of contact. The person who wants to access one-to-one mentoring must also concurrently be receiving clinical treatment for their eating disorder; they set goals with their mentor to achieve in that stipulated time frame and that relationship is intended to only occur within this.

In these circumstances, the person providing the peer work is not necessarily in contact with other clinicians who are managing the persons care – it's certainly not standard practice. For some, they don't strongly feel the need for that contact, possibly because the organisation is heavily involved in supervising the program. Although, for others, there is some desire to be so that they have a clear and holistic view of the treatment approach. Generally, though, mentors see their role to instead be to provide context for example, in explaining why clinicians might be asking or stipulating a certain course of action, to help motivate the person suffering the person with an eating disorder to engage with that treatment.

The wellbeing of the peer workers within state-based eating disorder organisations is protected and maintained through regular debriefs with a supervisor or lead mentor following mentoring sessions particularly early on in someone's experience as well as regular group sessions. It is clearly communicated to those accessing the peer work that they are to respect the boundaries of care. However, as something of a natural consequence of the connection between the person providing support and the person accessing it, there are occasions when the peer worker is required to manage a crisis of some kind, acute presentation of eating disorder symptoms, or worse, suicidal ideation etc. Moreover, the mentoring relationship can also involve conversation around how to manage eating disorder thoughts wherein the peer worker can share strategies they have personally found to be effective.

Overall, this type of mentoring appears best positioned at a point when the person experiencing an eating disorder is motivated and proactively progressing towards recovery and is in outpatient or community care.

One-to-one coaching

An alternative type of peer work that is delivered one to one is referred to as coaching – this is typically provided by those who have completed the Carolyn Costin training (but not always). Several peer workers who have completed the Carolyn Costin training and achieved accreditation in this way were interviewed as part of this research.

This training has been developed and is facilitated by Carolyn Costin, a leading advocate for peer work in eating disorders in the United States. It takes approximately one year to complete and is positioned as being a fulltime career choice. Her perspective is that the 'typical' peer worker is akin to a mentoring role whereas a coaching position is more involved with the practical support, such as at mealtimes, and ideally embedded within the care team; note that the Costin model offers training for both types of peer work. The coaching training program involves exams, an internship, and access to a clinical supervisor (Carolyn Costin). It also includes exposure to several challenging situations.

Ultimately, this approach is a commercial one because to complete the coaching program, people typically need to self-fund and accessing coaches is then an out-of-pocket expense. It is likely that fewer coaches than mentors exist in Australia at present, but this number does appear to be increasing.

One-to-one coaching is the most all-encompassing form of peer work potentially due to the lack of regulation and boundary setting that is somewhat inevitable when someone provides clinical care alone. For example, those offering the coaching style of peer work talked about persons with lived experience being able to access them into the evening, providing in-the-moment support and a high degree of crisis management amongst those still relatively unwell. Services available include home visits for meal support and dealing with intrusive eating disorder thoughts – all of which is in accordance with the intentions of the Carolyn Costin model (but perhaps not in one-to-one coaching whereby the peer worker hasn't completed this training).

> *"For example, we have coaches who are trained and they help families who are doing FBT – family based treatment – and let's say the family is having all the meals with their daughter with anorexia, but they're exhausted and need some help with that. So, the coach can come in and help do family-based meals, and they might just be hired to do meals at lunch, to go and meet the kid at school and have lunch with them at school. But it can go all the way up to the coach going to the family's house and doing a live-in and trying to help prevent – let's say the kid is on the verge of needing to go the hospital or a higher level of care – some families are hiring coaches to come in and live with them for a while and see if they can try to prevent hospitalisation or residential treatment."*
>
> Industry stakeholder - international

However, the responsibility is regardless felt to be high, at times challenging, and the degree of involvement can be viewed negatively by clinicians. One clinician was strongly against one-to-one coaching because of an encounter where a 'mentor' undertook narrative therapy, and another where a 'coach' provided meal support on Zoom. They felt that these peer workers were instigating care models that were not appropriate (or welcomed) and overstepping both the peer workers' personal boundaries but also those of the clinician. This is likely a direct consequence of a lack of regulation or coordinating body overseeing this type of peer work.

Moreover, recovery coaches as trained by Carolyn Costin operate privately with the onus strongly on them to seek out their own psychological support to maintain personal well-being. Whilst they can access Carolyn Costin for ongoing supervision on the delivery of care, there is a financial cost attached to this and it is not a regular or structured occurrence in the way that supervision is enforced within Australian eating disorder not-for-profit organisations. It is possible that this gap in the model could yield problems further down the line, strongly impacting the peer workers mental wellbeing simply due to the level of burden they shoulder.

Residential/hospital-based peer work

A final type of peer work that is offered by a range of care providers is that provided within individual hospitals or centres for inpatients. This type of peer work appears to be the most ad hoc and varies between health services, and therefore the most problematic in terms of risk. People providing peer work are asked to undertake a range of activities, including meal support. This type of peer work does not appear to be strongly structured and supervision is available, but not always fully enforced because it is centre dependent.

The feedback from peer workers situated in residential, or hospital settings is, therefore, somewhat mixed. Two of the people interviewed indicated that they are not – or were not - fully briefed regarding the people they are expected to care for and are rarely included in multidisciplinary team meetings making it hard for them to prepare and adequately support an individual. One peer worker specifically made mention of a lack of supervision and support for her personal wellbeing in this setting. This is not true for everyone though. Another peer worker felt positively about their experience and mentioned being well embedded in the care team, attending MDT meetings and having complete visibility of patients' care.

5.2   The need for increased investment in an eating disorder focused peer workforce

Reflecting the findings from the literature review and consistent with the policy direction regarding peer work in mental health, this research has identified a range of perceived benefits for those accessing and delivering peer work in eating disorders. It is worth noting at the outset that whilst the primary data discussed here is compelling, it is also by its very nature subjective. Hence, additional work is required to formalise these outcomes through objective program evaluations or RCT-style research. In this section, the perceived benefits are as described by persons offering or accessing peer work, clinicians, and industry advocates for peer work in eating disorders.

5.2.1   Benefits of a specific, eating disorder focused, peer workforce

The NMHC peer work guidelines describe two main types – 'carer to carer' and 'direct peer'. In keeping with this, this section shows that the benefits of these two types of eating disorder peer work are also distinct – each has its place and value but for different reasons. Accordingly, this section will discuss their relative benefits separately.

Overwhelmingly though, and as shall be discussed in further detail later in this report, there is clearly a benefit to peer work in eating disorders. There is also a strong case for a specific focus on this compared with peer work in mental health more broadly due to the unique nature of the challenges faced by people experiencing an eating disorder.

Benefits for people directly experiencing an eating disorder

All but one of the participants interviewed for this study talked about the benefits of peer work, even if they felt there were areas that needed to be improved.

There was broad consensus that a primary benefit of peer work for people experiencing eating disorders is that it provides hope that recovery from an eating disorder is achievable, because the peer work is tangible proof that it is possible. This was felt not only by those who had recently accessed peer work, but also those providing it now with the benefit of hindsight. For example:

> *"They gave me a sense of hope towards recovery, I suppose, or that there were things available that I could do to head in the right direction, even if I didn't want to go in that direction yet. At least I knew that I should."*
> Recipient of peer work, lived experience of an eating disorder

> *"I'm just thinking back to when I was in the depths of my eating disorder. I would have liked someone to have been there to say, 'recovery is possible'. You know it. It's so worth it. Yes, you're stuck in this bubble. If you're in the eating disorder right now, and it seems like it's your life because you're in that bubble, but you don't realise what else is out there until you step out of that bubble. And that bubble bursts. And I think that with peer support and peer mentoring that really provides those people with that hope".*
>
> Peer worker, lived experience of an eating disorder

> *"…if a patient is really stuck in their eating disorder, they can look at someone on the other side [a peer worker who has recovered]"*
>
> Clinician

> *"… because there's no way to help people really see that they can be fully recovered unless they're exposed to people who are… if they don't get to see anybody who has recovered then they're not going to believe they can do it – why would they?"*
>
> Industry stakeholder - international

Because peer work can happen in a community setting too, that proof of process can be observed in the real world. For example, one peer worker explained that if they went to a café then the person accessing peer work would observe them enjoying eating and drinking whatever they felt like, without them experiencing any fear or discomfort. This is corroborated by someone who accessed peer work and talked about how it was heartening to observe that person having normal eating behaviours in public (especially given this – eating in public - was a specific goal of their own). Moreover, peer workers have the benefit of having gone through that recovery process already, meaning they have strategies and advice they can offer to enable someone to reach their own recovery milestones.

> *"It was cool to see her eat whatever she wanted. We did it a few times, it was my first time eating out and I did it with her cause It felt the safest and I knew that she would be able to support me."*
>
> Peer worker, lived experience of an eating disorder

Further, by talking about their experience of their life in recovery, peer workers offer insight into a life that is not defined by an eating disorder. Hence, it's not simply the case that they provide hope of achieving an end goal – they can paint a picture of what that end goal might look like. In essence, they demonstrate 'normality' and an everyday life that's not constrained by eating disorder thoughts and behaviours that someone can visualise for themselves. Interviewees believed this helped to strengthen people's desire to recover and bolstered their motivation to persevere through treatment even when encountering challenges. It is possible, therefore, that in this way, peer work might ultimately improve treatment compliance and completion rates (although a formal evaluation would be required here).

> *"More like a continuous guide… rather than just recovering out of behaviours or thought patterns and stuff, but then how to live your life post recovery."*
>
> Recipient of peer work, lived experience of an eating disorder

As will be discussed in greater detail later in this report, the point at which someone accesses peer work in eating disorders varies hugely and there are conflicting perspectives about the optimal point(s) for this type of intervention. Regardless, it was reported that some people access peer work when they are considering seeking treatment for an eating disorder, for example via eating disorder telephone helplines or live chat functions (as was the case internationally). On other occasions, people were exposed to peer work through e.g., in patient care. But ultimately, peer work may be able to increase the resolve of the person experiencing an eating disorder to take the crucial step of seeking treatment or to adopt a recovery-focused mindset, as well as help them understand and navigate treatment options.

Another benefit with peer work is that it can offset the negative feelings some people have towards clinicians who are demanding that they eat and gain weight as part of their treatment. People undergoing treatment for an eating disorder may feel that their clinicians don't understand them and are 'not on their side', which is described as isolating. Peer workers can empathise with this perspective and provide a safe space for people undergoing treatment to express these feelings and frustrations. At the same time, peer workers can also help to explain the purpose and benefit of the treatment. Participants in this research explained that people with eating disorders tend to be more receptive to explanation and advice from a peer worker (and so, perhaps, more likely to comply with treatment) because peer workers really do understand the challenges that person is experiencing, in turn reducing some of the feelings of isolation.

> *"I think that people with eating disorders often have a tendency to say things like, 'You just don't understand. You don't get me. You haven't been there so how would you know.' And you can't do that with someone who's recovered, they can't really pull that. It's a little bit harder in a way to say 'you don't get it' with someone who's been there, who's recovered. I think you can be a good role model when you're doing peer support. Not just a role model for certain behaviours... [redacted behaviours], but you also, you can be a role model for how to get better, you can also be a role model for the fact that being recovered is possible."*
>
> Industry stakeholder - international

> *"[A peer supporter can say] when the doctor hassles you, I know you hate it, but it's for a reason."*
>
> Clinician

> *"...so it's saying look to recover I had to do this and this helped me, it might not help you but to share that where as a clinician could say to them over and over again but they won't listen - because I haven't lived with this. And it's not saying, it worked for me, therefore you should do it, but maybe it can help or we can find another way..."*
>
> Clinician

> *"They want to be in recovery but then they don't and so if you have that peer support worker there who goes 'I know it's really bloody tough right now, but you know, just let's just stick it out, right, you know, think about that longer term goal of recovery. Yes, it's shitty that the treatment team are making you eat three meals and three snacks a day. Yes, they're saying you have to go into hospital. Yes, you have to do all these different exposure activities that are tough, but it's going to get your life back. It's going to bring you towards your goal of recovery'...If you've got a peer support worker cheering them on the side going, you can do it's worth it, then who knows, that might actually have an impact on their treatment."*
>
> Peer worker, lived experience of an eating disorder

People experiencing an eating disorder also described feeling high levels of shame around their behaviours, and/or the impact that their eating disorder is having on their families and other people who care for them. A peer worker is uniquely placed to provide a safe space where someone with an eating disorder can talk about their feelings and behaviours without fear of judgement or stigma, because the peer worker has likely felt or behaved similarly themselves. More broadly, peer work can also help people accessing support to realise that they are not alone in experiencing the thoughts and behaviours associated with an eating disorder. This level of understanding consequently facilitates a type of connection that is unique amongst the clinical care team, and again helps to reduce feelings of shame, guilt, and isolation simply because of the ability to truly empathise.

"Eating disorders make you withdraw from your life and socially too... I think once everyone got comfortable with each other [in the peer support group] I found it was pretty helpful having people to relate to, with similar shared experiences, and I was like 'oh my god I thought I was the only weird one'...but then yeah it was quite a common experience, so it was nice having that group dynamic"

Recipient of peer work, lived experience of an eating disorder

"...eating disorders are where depression was 10 years ago, it's not spoken about, it's swept under the carpet and there's this shame and the stigma. And so that's what I do with my recovery coaching and with all these things [other types of peer support and advocacy] - the aim of it all is to bring eating disorders out the shadows and into the light, because if we speak about it and people see that that I am not ashamed one little bit, people can take strength from that."

Peer worker, lived experience of an eating disorder

Further, the peer worker also recognises the differentiation between physical recovery i.e., achieving a healthy weight, the ability to eradicate eating disorder behaviours, and the resolution of eating disorder thought, but that all elements are essential to holistic recovery. They discussed how they can prepare the person still experiencing an eating disorder for the reality that they may not fully resolve eating disorder thoughts until much later in the process and / or that not ever encountering challenges was not necessarily realistic. As a result, peer workers believe the person in recovery has a more realistic perspective and is less likely to 'give up'.

"...[recovery is when] behaviours are not influenced by thoughts they have about food. When they're unwell, these thoughts influence behaviour...people get confused by that. They think they'll never have body thoughts, but you can and do and it's normal, but it doesn't change anything about what you do in that day [when you're truly recovered]."

Industry stakeholder – Australia (paraphrased)

Benefits for families and carers indirectly experiencing an eating disorder

Eating disorders usually have a distressing impact on family members and particularly in the case of paediatric care where the family bear significant responsibility in enforcing treatment approaches. Peer workers working with families have reported that they can help to relieve some of the pressure families feel, by providing an additional person who can provide non-judgemental support to the child and explain why a parent might be finding it difficult.

For example, one peer worker discussed how they had helped to improve family relationships affected by eating disorders, by working with people with an eating disorder to understand their parent/carer's perspective. Simply by explaining that a parent's angry response to a situation may be driven by fear for their wellbeing rather than anger at them per se.

In addition to these indirect benefits on the family gained by direct peer work, there is peer work also available between carers and families from several organisations. Many of the benefits offered by family peer work reflect the benefits outlined for the person with direct lived experience, in terms of hope, motivation, and connection.

> *"I realised how powerful my story was because other parents who are deep in the trenches and feeling like they're drowning needed to hear some positive news that you can get through this. And despite how bad it is and how terrible you're feeling, there will be better days ahead"*
>
> Recipient of peer work, family / carer experience of an eating disorder

Moreover, peer work for families and carers is perceived to be particularly helpful in the case of Family Based Therapy where the role parents (and other family members) are asked to take on can feel confronting. This is because FBT involves parents taking back control from an adolescent (to 're-feed' them), rather than encouraging increasing levels of independence and ownership as a child gets older. Peer workers can not only express genuine empathy with the situation but also attest to – thus reinforcing – that what they are doing should contribute to their child's recovery (even if the child resists).

> *"Validating the persons experience and coming from a place of no judgement, empathy, understanding - it's a very different dynamic than speaking to a clinician...to be honest, the last thing parents full of despair and exhaustion want is to be being told by a clinician out of a text book, you need to do this, you're doing this wrong - when actually they've got no idea what it's like to actually try and apply that at home."*
>
> Peer worker, family / carer experience of an eating disorder

Following on from this, peer workers can educate parents about eating disorders, and the rationale behind treatments, in a way that they can understand, because of their own experience. They can directly relate to the fear, confusion and wealth of emotion parents, family members and other carers report experiencing thereby giving greater insight into the rationale and nuance behind treatment options. Taken together, it is hypothesised that the hope, reassurance, and education provided by peer workers empowers parents and carers to persevere through treatments, including FBT, and therefore increase the chances of successful treatment.

> *"It's ok hearing it from someone who has learnt it at school, but it makes all the difference hearing it from someone who has lived it."*
>
> Peer worker, family / carer experience of an eating disorder

> *"If you upskill the family to feel like they're able to support somebody, the outcomes are going to feel different or be different. Hopefully by upskilling and supporting the families, to be able to support the young person through their journey of recovery, recovery is more likely because you're not putting a young person into a family who feel unskilled, scared. Isolated; you know incapacitated by the illness."*
>
> Recipient of peer work, family / carer experience of an eating disorder

In some cases, peer workers who have had an eating disorder themselves may also work with parents (i.e., direct peer to carer, rather than carer to carer) to help them better understand the experience of their child, so they are more equipped to empathise and support them.

> *"The parent wanted to have a follow up session with me [after the session had finished with her daughter] just for her to understand how that session went. If there are any insight. She basically was like I want to lift the lid on her brain. Can you tell me what's happening when she says this? What does this mean when she says that? What's going on in her head? Can you explain to me why she is behaving in this way? And so really, just give parents an insight into the inner workings of an eating disorder and also, you know, things for them to look out for."*
>
> Recipient of peer work, family / carer experience of an eating disorder

Education can also be a two-way process. One peer worker described how she was often a conduit between treatment teams and families; helping treatment teams to understand a family's perspective better (as well as vice versa), and therefore improving the relationship between the two. Another peer worker felt this is a way in which the role could usefully be expanded:

> *"Too often we're shut out [parents] and we should be included in the conversation... you won't get a more valuable person as part of the treatment plan."*
>
> Peer worker, family / carer experience of an eating disorder

> *"It's quite commonly fed back to me is that we act like translators between the parents and the team. And if something's not quite sitting right, we kind of put it into the lived experience perspective and then you can see the clinicians going 'I haven't thought about it that way' and then the parents also."*
>
> Peer worker, family / carer experience of an eating disorder

Family peer workers also offer parents a connection with someone who genuinely understands what they and their family is going through when it's unlikely any of their peers can relate. For example, one parent explained that when their child was diagnosed with an eating disorder, they didn't know any other parents in that situation, so their family and friends couldn't fully understand what they were going through. This was felt to be very isolating, like how the person experiencing the eating disorder feels.

A peer worker also explained that connecting with family peer workers, and other parents, can sometimes help to alleviate guilt that parents may feel (e.g., because they hadn't been able to prevent their child from developing an eating disorder), by showing them that other families were going through the same thing. The emotional wellbeing of families is not only an important benefit for the families themselves, but also in ensuring parents are able to effectively support their child through treatment.

> "That's my thing, I want parents to know it's not their fault, I don't want anyone to go through the hell that we went through... I feel like I'm one of the lucky ones, we got through it in 15 months, but every day was a nightmare."
>
> Peer worker, family / carer experience of an eating disorder

> "So I think for me that's why I'm so passionate about supporting parents to have new skills, to be able to do what clinicians find so hard and to make that OK with them. Because you're fighting your head as well, you're not only doing a new skill, you're actually working against the stigma that's in your head. You're working against isolation from family, and your normal supports... because you don't have the capacity to have your normal supports, and quite often those normal supports don't understand eating disorders."
>
> Recipient of peer work, family / carer experience of an eating disorder

In addition to emotional support, family and carer peer workers give practical benefits for example in helping people and families affected by eating disorders navigate treatment pathways. This might range from a one-off conversation, with a peer worker providing contact details for services (e.g., via a telephone helpline), to deeper conversations about treatment pathways and options again helping to reduce feelings of isolation and confusion.

Similarly, a peer worker can work with parents who are concerned about their children exhibiting disordered eating patterns but who are not formally in treatment, or whose children were on waiting lists for treatment.

> "I'm looking at pairing people that don't have a treatment team with a great dietitian, a psychologist, you know, whatever else is needed, a GP. We have a compendium of resources that we've compiled, with recommended GPS that we know are really sympathetic to eating disorders, same thing with the psychologist and dietician. And so, it's about getting them in with those people and creating a really good team around them up. We run support groups as well, so kind of clicking them in with the support groups as well. And I've got a recommended reading list, so, making sure they've got access to as many recovery resources as they possibly can."
>
> Peer worker, family / carer experience of an eating disorder

One peer worker recounted how the education and resources they provided had been sufficient for some parents to help their child, without the need for formal clinical treatment. However, the broader issue of accessing peer work when someone is not in treatment is controversial and requires further investigation. The stakeholders consulted for this study all emphasised the importance of eating disorder peer work being provided as an adjunct to clinical care; not as a replacement for it.

Benefits for peer workers

All the peer workers who participated in this research believe peer work is an opportunity to give back to their community (i.e., the community of those who have experienced an eating disorder) and felt a sense of satisfaction in helping others.

> *"I had been resigned to having this severe and enduring eating disorder, that you know, I was never going to recover, basically I was going to die and that was it and I didn't die and I wanted to sort of go right, well here I am and I want to stand up for other people who are going be told the same thing and prove that there is life on the other side and that full recovery is possible. And I think the way that I felt that I could do that and really have an impact on people was to actually help them on their journeys."*
>
> Peer worker, lived experience of an eating disorder

However, the perceived benefits of peer work extend beyond this. Peer workers and others in the sector tended to describe peer work as a mutually beneficial relationship if appropriate safeguards and support are in place to manage risks (as discussed elsewhere in this report). Specifically, peer workers felt that discussing their own recovery journey, reflecting on how much they achieved, and how their life had changed for the better, helped to solidify and strengthen their own recovery and in some cases progress them even further along that journey.

For example, some participants indicated that that providing peer work can take someone from a place of being 'in recovery' to 'recovered', by forcing introspection and reflection. Although a formalised definition of these two concepts has not been agreed upon in the context of eating disorders this might, for example, mean a person moves from still experiencing and needing to manage eating disorder thoughts to prevent eating disorder behaviours from occurring, to a place where they feel free of their eating disorder, without thoughts or without the emotions attached to body image they had previously experience. Further, for those some of those 'in recovery', talking about their journey reminded them of the importance of continuing with, or reinstating, practices that would help to maintain their recovery.

> *"I think for me, it progressed my recovery. Like I was definitely recovered when I started, or you know, well established in my recovery, and it had probably been a good sort of 3 or 4 years where I didn't think I'd been engaging in behaviours and things like that. But I think it certainly progressed and made me become a bit more self-aware of some of the other things I could work on"*
>
> Peer worker, lived experience of an eating disorder

> *"It feels like a privilege to have gotten through my own recovery and to be able to help others grow and develop and get through recovery. Also it reinforces my own recovery, when I talk about things that were helpful for me it also reminds me and stay accountable for my own recovery."*
>
> Peer worker, lived experience of an eating disorder

Summary

In summary, the perceived benefits to the provision of peer work in eating disorders are largely consistent across a range of perspectives. The key points are that peer work in eating disorders provides hope that recovery is possible, it nurtures empathy and understanding with the situation, and reduces feelings of shame and isolation felt by the person experiencing the eating disorder. Importantly too, it addresses the gap left by clinicians in that it can offer an explanation to treatment decisions and offset some of the stigma and misunderstanding felt by those experiencing an eating disorder when interacting with their clinicians.

5.3   Contextual constraints on the current peer workforce offering

This section explores how the aspects of the current context (i.e., structural factors largely outside of the control of peer work providers) are constraining the scope of what a peer workforce could achieve with additional focus and investment. Given the benefits outlined in the previous section, it is clearly important to identify and address top-down contextual influences like limited funding for service delivery and evaluation and a lack of a centralised framework or coordinating body to guide service delivery to maximise the potential output from this type of service intervention.

First and perhaps foremost, these research insights highlight the limited funding available for peer work in eating disorders, specifically regarding service delivery. In short, there is a strong consensus that the number of people with eating disorders far exceeds the available treatment options, as evidenced by long wait list for services, and the same is true for peer work services.

> *"We have people coming to us every single day who want to volunteer for [eating disorder charity]...our problem is funding we don't have the funding to support that. We've got a massive waiting list. We need funding to employ another recovery coach, so we just keep a list of all these people and hope will get the funding."*
>
> Peer worker, lived experience of an eating disorder

Moreover, it is also noted that eating disorder peer work is not listed on the Medicare Benefits Schedule (MBS) although it must be highlighted that this perspective was put forward by a peer worker within the private sector. As such anyone who wants to access peer work through the private sector, for example, must bear the full cost of this which in turn acts as a barrier to accessing care.

> *"I think the biggest thing is a certification needs to be recognized in Australia because there are people that can't afford coaching, right? So, we need to be able to get it covered under Medicare and in order to get it covered under Medicare, it needs to be recognized in Australia...I had a mother and daughter come in yesterday and they were asking if [coaching] can it be covered under a mental health care plan? Are there any subsidies? [And I had to say] I'm really sorry there's not"*
>
> Peer worker, lived experience of an eating disorder

There is also a lack of funding available to undertake robust evaluations and RCT-style research into the optimal approach for eating disorder focused peer work. As outlined in the literature review, peer work in the eating disorder space is an emerging field, and while there is some evidence to support the benefits that it can achieve, relatively few evaluations have been conducted and those which have are somewhat limited in scope. This was described as a 'catch 22' situation by people working in the sector, as a strong evidence base for efficacy is essential to justify increased spending, and achieve stakeholder buy in, but larger scale peer work programs are required to demonstrate effectiveness which cannot proceed without large scale funding.

Related to this, another key constraint is the lack of an overarching framework that specifies objectives, target outcomes and indicators, and the appropriate positioning of peer work within the existing treatment model. As a result, there appears to be little cohesion between the intentions of peer work and the type of work that is provided for different diagnoses, in specific contexts, or at specific stages in treatment (e.g., when symptoms first emerge, upon diagnosis, in residential or hospital treatment, and post-treatment/in the community), potentially limiting the efficacy of this type of intervention.

This is further compounded by the fact that the lack of an overarching framework means that the way in which peer workers are recruited, supervised, and trained is determined by each individual provider leading to significant variations in service delivery as is described in more detail later. Likely related to the lack of an overarching framework, some participants reported that peer work is perceived by some to be an add on to treatment which is 'nice-to-have', as opposed to a crucial role which can have an impact on patient outcomes.

Finally, there is currently no centralised body to oversee or guide service delivery of peer work in Australia, and this was identified as a key gap by several peer workers and sector stakeholders. A centralised body could develop a framework for service provision, ensure that peer work is consistently implemented safely and effectively, raise awareness and understanding of eating disorder support among consumers, health professionals, and other stakeholders and provide information and resources – however, this would only be possible through a clear policy position to that effect and adequate funding.

Australia is not unique in this respect with similar constraints reported by eating disorder organisations operating internationally (US, Canada, and the Netherlands). For example, in the US and Canada peer workers are not certified healthcare providers and therefore not eligible for funding through government healthcare systems or health insurance, there is a lack of policy direction and centralised public funding for this service intervention, and consequently a lack of an overarching framework or a dedicated coordinating body or association to oversee eating disorder peer work. International sector organisations also highlight the need for evaluation to understand exactly when and how peer work is most effective. Altogether, as with Australia, these limitations have flow on effects for how peer work is currently managed and delivered.

5.3.1   Summary and implications

The participants in this study who have experienced and delivered peer work (peer workers, those accessing support and sector organisations) are (with one exception) strong advocates for peer work and the benefits it can provide at all stages of the recovery journey, for both peer workers and those who access their support. However, there are few robust evaluations that can link peer workers to improved clinical outcomes or definitively identify the success factors in different contexts. It might be argued that reported improvements in the emotional wellbeing of both parties is sufficient justification for the expansion of peer work in the eating disorder space. However, pressing ahead without a solid evidence base may mean the full range of potential benefits of this type of work are not realised or that practices that result in negative outcomes are allowed to continue. This presents an opportunity for Australia to lead the way at a global level in implementing a nationalised approach that regulates and standardises eating disorder peer work.

5.4   Current landscape regarding peer work in the eating disorder space in Australia

Central to this section is to critically examine the efficacy with which peer work is currently being delivered regardless of the contextual constraints outlined above. At the simplest level, it is imperative that what is already being provided is done so safely and effectively; a first step must therefore be to address key factors for improvement prior to any expansion of this service, but to also apply these learnings in the development and implementation of a longer-term eating disorder peer work strategy.

5.4.1   Appropriateness of the current offering from a service delivery perspective

The National Lived Experience Workforce Development Guidelines recommend that peer work must be distinct from traditional treatment services within mental health, with a focus on emotive and relational connection. It is clear from this research that this view aligns with that of people with lived experience of an eating disorder – those who have accessed services and those who have provided or advocated for peer work – and potentially is even more strongly the case.

This is because to a large extent, suffering from an eating disorder represents a very real and constant medical threat due to the presence of both the physical impact of disordered eating and often – like in other mental health conditions – severe psychological symptoms such as self-harm and suicidal ideation. One peer worker described eating disorders as "an emotional and medical emergency always" and that "the person is in a life-threatening situation always and you need to share with that mind, you need to connect with them, connect them back to self, their community". It is also somewhat unique in the sense that recovery is possible but until the person experiencing the eating disorder actively engages with that process then progress through clinical care is limited.

> *"I think you have to be at a certain level where you're happy to talk openly and honestly and want to recover."*
>
> Recipient of peer work, lived experience of an eating disorder

This is also often compounded by the fact that presentation of illness occurs in paediatric care. The means that parents and carers are responsible for enforcing changed eating behaviours and the person suffering feels little autonomy over their life, and as though they have no choice over their own care and wellbeing.

This section will discuss two overarching themes regarding the integration of peer work into the existing care model. First, the question of when in the care pathway peer work should be accessed to optimise desired recovery outcomes and second, how peer workers should be position within clinical teams.

Positioning peer work on the care pathway

Treatment of eating disorders is highly complex, and the existing treatment model is not without its challenges. Although the goal of this research is not to go into detail about these, there are factors worth mentioning for the relevance to how peer work should be positioned.

First, as noted above, underpinning all care is a need for the person suffering to engage with recovery for successful outcomes to occur. However, those with lived experience of an eating disorder and some clinicians report that high levels of stigma, negativity and a lack of empathy can exist within clinical teams. This leads to people with lived experience feeling disconnected from treating physicians and like they're a 'hopeless case'. They describe the illness overall as being very isolating and experiencing strong feelings of shame that can be exacerbated by clinical teams (and families where relevant).

> *"I was traumatised by the health system...told I was a hopeless case...turned away, experienced stigma from clinicians and just felt like 'I just want someone who understands'...wanted a psychologist who had been through it and survived"*
>
> Peer worker, lived experience of an eating disorder

Altogether this doesn't put the person suffering in the optimal frame of mind to want to engage with recovery or believe that its possible. But this can be offset by access to peer work which, as described previously, offers hope, empathy, reduces feelings of shame, and triggers motivational recovery behaviours.

Similarly, accessing peer work was described by one person suffering from an eating disorder as the first time they felt like they had choice over their treatment and care. This individual had recently transitioned out of the family-based therapy model and had chosen to access peer work on the advice of their dietician – and felt empowered by this decision.

> *"I was motivated to try it because I hadn't found anything since I turned 18 that offered the support that I wanted or needed...It's motivating...inspired by others...not much available to help with recovery so its good to connect with others who have that experience too and to be challenging things with them."*
>
> Recipient of peer work, lived experience of an eating disorder

Furthermore, perceived gaps in care remain in part due to conflicting perspectives around what defines recovery wherein peer work may offer a solution. Some participants report that clinical care focuses primarily on achieving a 'healthy weight' as the target outcome, for example, with lesser focus on the transition to everyday life and ongoing coping strategies. Their perception therefore is that peer work "addresses the gap left by other clinicians" in that it provides a safe and trusting space, free from stigma, shame, and judgement in which a person can be truly authentic – and learn and be motivated by someone with related experience to progress beyond what a clinician – without lived experience – might believe is a good indicator of recovery.

> *"I have clients who aren't receiving any clinical support and who, you know, say they've been kind of in pseudo recovery, but they've realized that there are these thoughts that they have still cling onto and they really want to get rid of those last little ones."*
>
> Peer worker, lived experience of an eating disorder

An important issue raised by peer workers themselves was the need to educate those on the recovery pathway that it's not the case that they will never have challenges in the future – whether these are about body image or other anxiety or stress issues – rather, the way they respond, process, and feel about these challenges differs.

Importantly though, peer work should not, at any point, be a replacement for traditional service delivery – there is a strong consensus on this being an adjunctive treatment only. The challenge at present is that there is no standardisation of how and when peer work should – or is best placed to – occur within the treatment model. The one consistent is that people who access these services should ideally also be in clinical care. Indeed, some services, particularly those facilitated by state-based organisations, stipulate that this is a requirement for participation, while others will support people who are considering entering into treatment (this appears to be more common among recovery coaches) or those who are on wait lists for treatment (particularly as the demand for treatment has increased in the context of the COVID-19 pandemic).

Deeper consideration and exploration of the value of different types of peer work at distinct points along the recovery journey and care pathway will therefore be essential going forward. However, this research suggests that group sessions may well be best suited to a point whereby attendees are at a healthier weight and able to resist some if not all intrusive eating disorder thoughts; and, that one-to-one mentoring for a fixed term duration seems suitable for supporting people in achieving specific goals related to living free of an eating disorder. In both cases, the defining feature is a recovery mindset and some level of ownership over that process. On the other hand, one-to-one mentoring, and coaching – if properly supervised - can also be accessed in situations whereby the person is not yet in a recovery mindset or perhaps is in the early stages of doing so (or possibly even before commencing treatment) and therefore occur within inpatient care, for example.

Collaboration with the broader clinical care team

Multidisciplinary care is generally best practice across healthcare, and this is certainly also the case in eating disorders. The objective of care necessarily changes as recovery progresses meaning clinicians may have a greater or lesser involvement at different points; collaboration between clinicians also means something different at different points.

When someone suffering from an eating disorder is in residential care, for example, the multidisciplinary team undertake case reviews together thereby ensuring knowledge sharing and collaborative approach. In the outpatient and community setting however, this appears more fragmented. Not only does the responsibility for ensuring ongoing care rest more heavily on the person with eating disorders (i.e., once immediate physical or medical threat has passed) and the choice to engage with e.g., a dietician or psychologist is theirs, in some cases this is made more difficult by shortages in access to care. One clinician, for example, discussed that some peer work occurs whilst people wait for access to care, however this means there's no clinician oversight which could be problematic.

Regardless though, there appears to be a consensus that this collaboration should extend to the peer worker at least to some extent. Some peer workers would like to be actively involved in case reviews and MDT meetings especially those offering a higher level of involvement in the persons recovery, for example. Their perspective is that they would then be better equipped to support and facilitate the clinician care. Also, that they could provide the MDT with additional insight about the patient that could be useful to them – because a person with lived experience is likely to be more honest with a peer worker than a clinician. One peer worker who was regularly attending MDT meetings (in a hospital setting) reported that their attendance had indeed provided each of these benefits to them and the MDT.

> *"I think my use comes into play at multidisciplinary team meetings when they're discussing care plans, which is what a lot of what we do at multi-MDTs. The plan will be being formulated and quite often I'll think of something that either I have a lived experience of, or have other heard from other people, and I'll just say, 'you know, have you thought about this?' And quite often that might steer the conversation or the way their family supported differently...*
>
> Recipient of peer work, lived experience of an eating disorder

Also, that being an integrated part of the team provided them with a greater sense of safety and security in the role. Further, over time, this close working relationship had expanded the team's understanding of the peer work role:

> *"Being part of a team is what makes my job safe, it gives me a good understanding of what I'm part of and that makes me feel more settled in my job because where you're encouraging people to engage in services, if you don't understand how those services work and you don't feel really confident in those services, it's really hard to do your job well..."*
>
> Peer worker, lived experience of an eating disorder

Another peer worker, who did not attend MDTs but was in regular contact with their client's clinicians, gave an example of how being fully informed about the treatment plan helped them to ensure that they were working towards the same goals:

> *"I will be communicating with the rest of the multidisciplinary team. So, the dietitian, the psychologists, GP... understanding what their goals are, understanding what the current meal plan is, what the challenges are. Ah, and you know, working with my client on those so that we're on the same page...like she actually said it to me last night, I don't think I should be having 2300 calories anymore per day, I want to go down to 2100 and I'm like, well, no, that's the discussion that you need to have tomorrow around that...I'm not making a comment on that right now... here's the difference because everyone is on the same page all the time, and you're aware of what's going on in session. So then if I have a session with a client, they're like 'Oh well, I mean, so the dietitian said this', but I've already had an email from the dietitian saying this is what happened in session, and this is what needs to happen this week...then you know."*
>
> Peer worker, lived experience of an eating disorder

Others mention they would like to be more involved but don't believe its necessarily their place, because peer work has a different objective to that of the clinical team. For example, should a dietician set a particular goal for someone suffering with an eating disorder that feels problematic for them, the peer worker would explain why the dietician was asking or challenging them with that, rather than persuading them to do it. And, on other occasions, clinicians may not even be aware that the person is accessing peer work. Some peer workers who had little involvement with the MDT felt there might be both benefits and drawbacks to more interaction. On the one hand, they felt a two-way exchange of information could be beneficial (for the reasons outlined above), but on the other they were concerned that the people they were supporting might be less open and honest in their interactions with them, if they felt the peer worker was part of the treatment team and passing information on.

> *"As a clinician myself I understand why it is the way it is and the limits on it all, but I think more of a multidisciplinary approach could be helpful because a lot of the clinicians don't know the participants are doing the program and they're unaware of what the peer mentor can do."*
>
> Peer worker, lived experience of an eating disorder

> *"I don't feel too connected [to the MDT], as it is just voluntary it felt more separate. I would enjoy being more part of it, to be more across what happens and why…[But] I feel part of the rapport I build is also because I am more separate to the team…"*
>
> Peer worker, lived experience of an eating disorder

Moreover, much of the peer work discussed here highlights the importance of the person setting their own goals outside of the treatment paradigm which are then supported by their peer worker – facilitating feelings of ownership over their own recovery. These decisions are reflected back in an empathetic and explanatory approach rather than setting goals or being persuasive.

Ultimately, these issues exist because of the context. Currently, there isn't the infrastructure in place for an expanded and coordinated delivery of care that includes peer work outside of the larger state organisations; the awareness amongst many clinicians about peer work is low; there is a lack of clarity and cohesion about what peer work involves and how it should be delivered; and ultimately, a lack of funding to address these limitations.

> *"I think it's very important that the management at the service is really supportive and gets behind the peer support workers and build up an understanding of what their role is within the team before the team take on peer support workers or carer peer support workers, so there has to be defined roles….It's kind of new to a lot of clinicians. There are still some people that are worried about all kinds of things, and I think those things need to be sorted through, and talk through the benefits of having peer support workers and so forth, and their roles and the scope. [You need] really well defined job descriptions and ongoing education for the team."*
>
> Peer worker, lived experience of an eating disorder

5.5   Critical analysis of the existing peer work in eating disorders

As discussed previously, at a macro level there are significant contextual constraints on the expansion and formalisation of peer work in eating disorders in Australia, as well as a need to optimise its positioning against traditional service delivery. At a micro level, there are several limitations and challenges facing the delivery of peer work as it currently stands which must be addressed before expanding, and which are relevant for the continued development of this type of care.

Perhaps the most important is to first arrive at a consensus on what the objective of peer work should be and what the target outcome indicators are. Addressing this will have flow on implications for macro level questions like how peer work should be positioned, regulated, and funded because, simply, there will be clarity around what is/should be being achieved.

There are also widely acknowledged risks with peer work in eating disorders although the extent to which these occur has not yet been robustly investigated. These can likely be mitigated by standardising processes such as the training someone must undertake before being involved in peer work, and consequently standardisation of job positions and responsibilities akin to the standardisation that exists across healthcare roles. Moreover, there are several unmet needs in the peer space to highlight which yield insights on the main considerations for a successful ongoing peer workforce. Each area will be discussed in turn in this section.

5.5.1   Objectives and outcome indicators for a peer workforce

The National Mental Health Commission Guidelines report the goals of peer work, as described by their participants, as being 'flexible (not driven by a prescribed agenda), that meaning making is foreground and that outcomes must be related to the values you work from in the first place'. There were several common values reported by participants as being significant – and interestingly, that peer work is valued for being non-clinical with the focus on human connection rather than clinical service delivery.

It is clear from this research that peer work in eating disorders is similarly valued for its distinction from the traditional clinical model, that it must be recovery orientated, and that it allows a greater degree of individualisation.

> *"I would say, and that's the beauty of coaching is that I can individualise. But to each client you know it's not this blanket, tick-the-box approach. It is literally where you at? What's your situation? OK and constantly tailoring that and changing it depending on what's required to get the highest efficacy."*
>
> Peer worker, lived experience of an eating disorder

> *Peer support has a place at every stage but where it's most helpful is individualised."*
>
> Industry stakeholder – international

An important starting point, therefore, is to agree upon a definition of what constitutes 'clinical' care and what constitutes 'non-clinical' care. Whilst this requires validation, an initial approach that also aligns with the national guidelines could be to define what peer work shouldn't do, before establishing outcome indicators. For example, peer work should not include diagnosis, the discussion or management of body weight and / or calorie intake, and it should not seek to problem-solve or address chronic psychological issues including past trauma or suicidal ideation. It can, however, facilitate the developing of coping strategies for reducing eating disorder thoughts and behaviours, offer empathy to the damage wrought by trauma, provide options in cases of danger regarding self-harm and suicidal ideation, and support the navigation of non-clinical goal setting.

These parameters, whilst important, do not equate to tangible outcomes, and to ensure peer work is adding value and minimising harm, it is imperative to be clear on these. Because it's in its infancy, there is a lack of evidence in this area – as was discussed earlier in this report – and there is the feeling for some those strategic adjustments and expansions of peer work should not be undertaken until a solid evidence base is in place.

> *"There's a lot that's not been thought through...so we need to validate it all...*
> *about 1 in every 6 it's [peer work] damaging for, is the thought...so we shouldn't do anything*
> *until there's evidence that it works."*
>
> Clinician and academic

To an extent, this is fair – however, as we have seen, peer work is already occurring hence it makes sense to leverage real world evidence alongside more formal evaluations, for example.

It is not within the scope of this work to propose a comprehensive logic for the expansion and delivery of peer work, but it is helpful to consider such an approach to support the broader conversation. For example, what is the issue we are seeking to address with peer work? How does this differ by stage in the recovery journey? What are the inputs, outputs and outcomes involved in this?

Here it is assumed that peer work aims to reduce some of the tension felt by people suffering with an eating disorder because of feeling isolated, shame, and not understood within the existing treatment model, and address a perceived gap in treatment regarding the later stages of recovery.

With that in mind, it is proposed that short-term outcomes include:

- Feelings of hope and motivation regarding recovery
- Improved emotional wellbeing through personal connection, reduced isolation, and reduced shame

Medium-term outcomes could relate to:

- Achievement of recovery-related transition goals such as eating in public
- Resilience to emotional triggers such that eating disorder thoughts and behaviours are overall resisted
- Collaboration and knowledge sharing with clinical teams

And longer-term outcomes might be:

- Increased adherence and persistence to clinical treatment plans
- Reduced burden on clinical services
- Resolution of eating disorder thoughts and behaviours

It is important to highlight that the above are for consideration only but reflect the positive outcomes discussed by participants in this research. What is also important to be mindful of is that these outcomes will differ depending on the perspective and context, hence a more in-depth and detailed mapping of the program logic will need to be completed.

5.5.2 Potentials risks associated with peer work in eating disorders

Anecdotally, there is strong consensus among those interviewed that undertaking peer work in eating disorders carries with it a greater degree of risk than peer work in other mental illnesses. Here, limited evidence of these risks occurring is reported and the existing literature (as outlined in Section 3) also describes limited evidence to that effect. However, this could simply be because peer work in eating disorders is in its infancy.

This section will first explore what is meant by the term 'risk' in this context before outlining the potential risks proposed by participants and discuss any occasions where these risks have manifest in negative outcomes.

What is meant by the term 'risk'?

In its simplest form, the term risk refers to the potential for a negative or undesirable outcome. Put another way, a risk may relate to the lack of certainty in a positive outcome and / or the maintenance of the status quo wherein this is a favourable state.

Regarding the risks related to peer work in eating disorders, there is a risk in not acting such that nothing in the current landscape changes or improves – this is risky in the sense that peer work is not currently set up for success and there's a lack of evidence guiding appropriate protocols. In addition, there's a risk in acting but in such a way that outcomes are not optimised and / or there are negative impacts on vulnerable individuals.

In the first instance, not acting i.e., not advocating for public funding, or not investing in adapting the NMHC peer work guidelines to make them relevant to eating disorders, and ultimately not standardising and expanding the peer model in eating disorders could mean:

- Limited parity of access to a service that could make a very real difference to clinical outcomes and mental and emotional wellbeing, because of a lack of public funding (and which could, in turn reduce pressure and demand on clinical services thereby representing an attractive cost-benefit equation)
- Peer work is not sufficiently tailored to eating disorders, thereby limiting efficacy or in some cases, causing harm
- The peer work that is already carried out is not optimised to deliver effectively on outcomes, meet demand, and again may cause harm due to a lack of standardisation, regulation, and evidence-based approaches.

Similarly, acting but not doing so in the most effective and informed way possible could also result in suboptimal care outcomes. Common to both not acting or not acting properly – and perhaps the most important factor to be mindful of - is the risk of harm to those involved, particularly to the person accessing peer work, and to the person delivering it, as outlined below.

Potential risks to the person delivering peer work

Potential risks to the person delivering peer work include:

- Being triggered by the content of their interactions with the person suffering from an eating disorder, which in a worst-case scenario could result in relapse.
- Delivering peer work when they themselves, or in the case of families and carers, their family member/s, are not at a sufficient level of recovery leading to eating disorder thoughts and possibly behaviours, also ultimately ending in relapse on occasion.
- Not being properly trained and equipped to manage the emotional burden of trauma, self-harm, or suicidal ideation that is often revealed in a trusting peer relationship.
- Not being provided with adequate supervision/support that would provide peer workers with the help they may need to process and deal with particularly difficult or triggering conversations and / or in boundary setting.

There was consensus among the participants in this study that providing peer work has the potential to trigger relapse for the peer worker, if they are not adequately recovered. For example, if the person accessing peer support discusses issues like intrusive eating disorder thoughts and destructive behaviours, including suicidal ideation, and negative comments to the peer worker. This is also the case regarding family members or carers wanting to provide peer work when their family member is still unwell.

"And I would say that they need to be absolutely 100% sure that they are very, very well recovered. You will get things thrown at you that you know if you're not fully recovered, they would be highly triggering things...you know about clients call me fat. I've had clients say, well, I don't want to recover, I'm going to end up looking like you because...you know all those kind of things...so you've got to be so sure that stuff is just not going to affect you at all. You know it's just like, yeah, whatever, I don't care."

Peer worker, lived experience of an eating disorder

However, the definition of recovery is contested in the context of eating disorders and varies depending on whose perspective is being considered. Most importantly, there is some agreement amongst people with lived experience of an eating disorder that this definition should be developed by people with lived experience and that a clinical perspective is not always the most appropriate, rather the peer worker themselves are the best judge. For example, the criteria for recovery as defined by one state organisation as the absence of eating disorders behaviours rather than the absence of eating disorder thoughts, because the feeling is that someone can't be expected to never have an eating disorder thought and that this is based on self-report. This is a transition from psychometric testing that was previously used but the benefit is described as the peer workers are empowered, and the organisation needs to trust and honour their judgement.

It is noteworthy that all the peer workers participating in this study perceived themselves to be at an adequate level of recovery to protect them from the risk of relapse. It was also reported – as has been mentioned previously – that undertaking this type of work tended to solidify recovery even further, in their minds, implying that there is likely to be a recovery threshold at which people can peer workers with minimal risk to their own wellbeing.

However, whilst it is certainly important to incorporate the lived experience perspective, it needs to be accompanied by an objective assessment of recovery. This is recommended given, if someone is not adequately recovered, they may be unlikely to recognise this in themselves.

> *"As someone who recruits as well, sometimes people who say I've got nothing at all [to having triggers still, etc]. That's almost a bit concerning because maybe they don't have that self-awareness, perhaps."*
>
> Peer worker, lived experience of an eating disorder

> *"Recovery / a recovery definition is very different for most people...recovery is weight restoration, can they function in society, are they working, studying etc...but you can tell when you talk to someone who thinks they're recovered vs. someone who actually is...it's their perception of the world, of food etc."*
>
> Peer worker, lived experience of an eating disorder

For example, one peer worker in this study did relapse whilst providing care – and they also felt strongly that no one else could define what recovery meant for them other than themselves. Whilst it is hard to unpack exactly what triggered the relapse, this worker did refer to increasing levels of stress because of the peer work amongst other reasons which, it was implicitly communicated, resulted in eating disorder behaviours to manage that stress.

> *"What is defined as recovery is contentious. Usually, they want 2+ years recovery but that means symptom free...but lots of people have issue with this as who gets to decide...you might define recovery differently to a clinician...it's your trauma so who gets to decide? It's difficult, and they've applied a blanket criteria."*
>
> Peer worker, lived experience of an eating disorder

The question of how to assess someone's recovery status (for the purposes of eating disorder peer work) is thus a complex one and likely requires further investigation. Currently, there are inconsistencies in how recovery is defined and assessed. Approaches include a minimum time frame since recovery (most often 2 years) and informal assessments undertaken during recruitment like observing speech and mannerisms. There is also a degree of self-assessment expected – and desired by many with lived experience - as described above.

Given the anecdotal evidence gathered here wherein only one peer worker reported relapse and only one other example was given by a clinician, these approaches appear to be mostly successful. But, taken in the context of some of the literature, this indicates that a relapse occurring because of not being sufficiently recovered remains a real risk, a risk that would likely increase proportionally to the size of the workforce.

It is also noteworthy that some industry stakeholders believe that self-assessment is not sufficient and suggested additional approaches that could be used to determine sufficient levels of recovery, including conducting interviews in food environments to observe the persons response. Additionally, one must be mindful of the terminology used - recovery, and relapse, because some people with lived experience felt these to be inherently negative and implying failure. The solution doesn't appear to be to immediately use alternatives, rather to be conscious of the framing to avoid any subtle message of failure toward the person with lived experience and ensure too that they're comfortable to share if they are feeling vulnerable without fear of negative ramifications.

Furthermore, it is certainly possible that someone delivering peer work could be triggered by their interactions, regardless of their perceived recovery status, and without resulting in a full relapse of eating disorder thoughts or behaviours. Rather, a 'trigger' could simply arise due to similarities between the peer workers own journey and that of the person they are working which elicits moments and feelings of trauma or shame, or even frustration, that readily resolve themselves. Alternatively, these similarities may prompt the peer worker to consider issues they still need to resolve.

> *"That could be a testament to where I'm at with processing my stuff. My back story if that makes sense. Like, I've dealt with the eating behaviour stuff and maybe there's more to work on with my past"*
>
> Peer worker, lived experience of an eating disorder

For example, one peer worker discussed an occasion where they felt frustrated by the person they were providing care for, and like 'they just wanted to shake her', because the tactics they were using to restrict intake were the same ones they had used when in a pseudo-recovery state i.e., felt they were recovered because they were eating but still managing restriction through veganism, for example. This worker described how they connected with the supervisor on the issue and was given additional training and resources on how to broach the topic and subsequently achieved a good outcome. Another peer worker explained that she would draw on Internal Family Systems (IFS) therapy to deal with tiggering issues that might come up when delivering peer work, for example, by pausing the session momentarily to step back from that triggering thought.

As suggested above, this type of risk is currently mitigated through training and supervision, but the level to which supervision is enacted varied notably. The larger state-based organisations represented in this study reportedly ensured that debriefs are carried out by a lead mentor (or on occasion psychologists) after every session, at least at first, extending out to monthly and supported by group sessions on a less frequent basis. The approach with the latter could be to discuss around a particular theme peer workers were encountering in their sessions, ensuring transfer of knowledge on how to effectively manage these issues. International stakeholders also discuss how frontline volunteers meet monthly with more experienced team leaders who mentor the mentor or that regular check ins are facilitated.

> *"We do check in after every session, how the mentor is going, not just for the sake of their relationship with the participant, but also how they're travelling along as well. How we can help them and self-reflective practices."*
>
> Peer worker, lived experience of an eating disorder

> *"The group supervisions really have been very helpful as well, so once again you're as a team and you can sort of see common themes that are coming up in sessions."*
>
> Peer worker, lived experience of an eating disorder

On the other hand, smaller inpatient care providers do not always find the time to conduct these, perhaps because they are managed by clinicians who experience significant demands on their time. Independent private sector one-to-one coaches also do not appear to have regular formal supervision (note those trained by Carolyn Costin are able to receive this directly from her, for a cost but it is an ad hoc service) although they are expected to ensure their own clinical care continues in its place. One peer worker, for example, said that although supervision was meant to happen weekly it rarely did and they also felt that when they did raise problems they were facing, not just related to their eating disorder, but because of the competing demands and needs of a multidisciplinary team, their issues were overlooked and not properly addressed (which created stress and ultimately was a factor in this person's relapse as noted above).

A number of participants highlighted the importance of peer workers feeling comfortable that they can openly discuss concerns or triggers with a supervisor, without fear that this will impact on their perceived ability to do the job or their job security. Some felt that a more experienced peer worker, or clinicians with lived experience, might be best placed to offer this.

> *"I think my own worries were about, you know, if I'm having a bad day, are they going to think that it's not going to work, or I am too vulnerable… But the longer I've worked there, and probably seeing other clinicians and other team members have bad days, that made it feel a bit more normal to me. But I was definitely worried and thinking, am I going to always have to completely OK and 100%, like with a game face on. I sort of did go through that process initially of trying to over-prove how well I was."*
>
> Peer worker, lived experience of an eating disorder

Like with any provision of healthcare, training is essential to ensure care providers have the proper skills required – the same is true with peer work. All participants discussed training they provided, had facilitated, or undergone. This varied widely but included topics like how to manage difficult conversations and specifically crisis management (including suicide prevention), boundary setting, active listening, motivational interviewing, escalation criteria and procedures, and understanding the support that is available to them, as well as the remit of their role and program/organisation-specific information. In some circumstances, training occurred over two days whilst in others, training options are ongoing. International stakeholders made use of case studies and scenario practice and talked about shadowing / direct mentoring, a practice which also occurred in Australia with some care providers. A couple of the eating disorder peer workers noted that they had completed mental health first aid training. Some eating disorder peer workers were provided with written manuals, which they revisited regularly to help them deal with particular scenarios or challenging situations. One of the international sector organisations consulted provides its eating disorder peer workers with several 30-minute online courses that can be revisited at any time. One area where a strong consensus exists is in the need for training on how and what to share about one's recovery story in a way that is both effective and safe, including the clear parameters that govern this process such as avoiding mentioning weights, calorie intake or eating disorder behaviours that someone struggled with.

Most eating disorder peer workers interviewed felt they had received adequate training, although this was not always the case. Certainly, gaps exist and training varies in context between care providers. One clinician reported that the training is often not specific enough to the job description implying variation is, to some extent, essential. Indeed, others suggested that training needs to be designed to specifically address the different types of skills required for different types of eating disorder peer work and settings, such as group facilitation versus one-to-one mentoring or in-patient versus community-based work. For example, a carer peer worker felt little was offered to them personally in terms of training. However, it is worth highlighting that the training needs for carer peer work are very different to those for people with lived experience who are providing peer work. There was some mention of the TAFE accredited Certificate IV in Peer Work (one participant had this accreditation), the Carolyn Costin accreditation, and Intentional Peer Support training, but mentions of training (specifically focused on peer work) being organisation dependent were more common.

> *"…I'm thinking maybe it [training] needs to be adapted to the specific demands and requirements – so outpatient, inpatient day, patient settings, whether or not it's someone one on one or in a group. Because obviously in a group there's a lot of other dynamics you have to consider, like you know that contagion effect whereas if it's just one on one, you don't actually have that. I think the training needs to be tailored for the kind of setting its in."*
>
> Peer worker, lived experience of an eating disorder

Some of the skills required for eating disorder peer work, e.g., active listening, were perceived to be consistent with other types of peer work, suggesting that broad peer work training, such as the Certificate IV in Peer Work would be beneficial. The carer-to-carer peer worker who had completed this qualification commended the rigorous interview process, as well as the content of the course (e.g., including legislation, storytelling, safety issues). They noted that it had been beneficial for them to complete a generalised peer work course, as it had enhanced their understating of some of the co-morbidities that often occur with eating disorders. However, many participants felt that there was a need for peer work training specific to eating disorders to equip peer workers to deal with the unique challenges involved, such as how to safely share recovery stories (as above) and how to deal with being exposed to potentially triggering conversations themselves.

> *"It has to be specialised. I mean it's not the same as dealing with someone who's got a drug addiction or an alcohol problem. It's not the same as dealing with someone who is bipolar or with schizophrenia. It's very, very different, and the level of support someone with an eating disorder requires, and the nuances of that, and the problems that you can come up against [are different]…"*
>
> Peer worker, lived experience of an eating disorder

In general, though, there are limits that are difficult to overcome. Training is likely to always fall short in preparing peer workers for certain conversations, for example one peer worker remarked on an experience where someone revealed they were a victim of childhood sexual abuse. This worker remarked that they not only wished they had known this before building a relationship with the person but also that they had been prepared with the language to use and how best to respond.

There are other risks that manifest largely as the result of the current context for peer work – specifically a lack of a centralised framework and organisational structure for this type of care. For example, people mentioned encroachment of boundaries most particularly in the private one-to-one coaching space, whereby persons with eating disorders are able to contact their peer worker at all hours. This is hard to mitigate, especially if the role expects this level of involvement and the peer worker is happy to provide it. Also, as one peer worker put it, "no one thinks rationally in a crisis" and so the natural response, regardless of training, is to help the person in need. It is noted that peer workers providing this type of out of hours availability view this as a crucial part of what they offer to their clients:

> *"…Then there's a lot of texting and emailing and stuff in between because coaching is not just about the sessions. Coaching is about being there in the moment when the person is struggling. So, let's say that it's late. It's 10pm and they all of a sudden start feeling like they want to binge but therapists are usually not in a position of wanting to have their clients contacting them in the night. But coaches, that's just what they do. That's their job so the person can call them and they'll sit on the phone with them and help them get through that moment."*
>
> Peer worker, lived experience of an eating disorder

> *"So what we know is that eating disorders don't have operating hours, it doesn't clock on at 9:00 o'clock off at 5:00, so my clients can reach out to me at any time of the day and get real time support around things. It's one of the big draw cards, so, you know, having their sessions each week, but then also having that our contact with me and just being able to draw my life experience to help with the practical aspects. Whether it's cleaning up the wardrobe of you, know old clothes, or helping them to go and shop for different wines, knowing that this is actually a very traumatic experience right now...those real practical elements that [are outside of the scope of practice of] psychologists and therapists."*
>
> Peer worker, lived experience of an eating disorder

It was also heard that there can be an overreliance on the coach by clinicians in some cases too – likely due to a lack of clarity and understanding of the remit of the role, as well as a lack of funding and resources in the eating disorder space. Whilst this may not be as problematic as more personal triggers, it could, as noted above, contribute to burnout of peer workers. It is therefore imperative to understand the longer-term consequences of this type of emotional involvement in someone's care and draw learnings from how e.g., clinical psychologists manage the impacts of working with people experiencing severe depression and / or suicidal ideation.

> *"I guess you know in thinking about safety, I'm thinking about safety for our clients, but safety for the peer support worker as well. I think we are so desperate for resource in the eating disorder space there is a risk of bringing people on quickly because they might add value and ease the burden, but we need to make sure that the peer support workers aren't going to be triggered."*
>
> Clinician

Another issue is how to manage relapse if treatment options are limited. Some peer workers talked about not being able to be treated at a facility they have worked at which can act as a deterrent in admitting when they are feeling triggered or vulnerable These are all issues that require an overarching strategy around education and infrastructure.

Potential risks to the person accessing peer work

Whilst the risks involved in peer work seem greater for the person delivering care, accessing care is also not without risk as was described by several participants of this research (although note, there was a skew to lived experience of anorexia nervosa). For example:

- Bodily appearance of the peer worker (be this 'larger' or 'smaller') which is likely to be most relevant to anorexia nervosa
- Being impacted by relapse of their peer worker
- The peer worker oversharing or over-stepping boundaries including in the content and the manner with which a peer worker shares their recovery story or strategies as noted above
- Not connecting well with the worker in a one-to-one situation i.e., not the right match
- Being triggered by others in a group session

Ultimately, there is a limit to which some these risks can be avoided. It is difficult to control for the body shape of a peer worker, for example, but educating them on this risk can help. One person who accessed peer work mentioned being surprised and a little jealous of their peer worker's appearance and trying to look at their dress size when they went shopping – but they were able to rationalise these responses in part supported by the peer worker eating and drinking normally and subtly but carefully ensuring they didn't see the clothes they tried on. Alternatively, one industry stakeholder suggested that peer workers who have the appearance of being underweight still shouldn't be employed at the outset. These types of issues are unique when compared to other

mental illnesses and reinforces the need for a specialist focus on peer work in eating disorders to ensure the appropriate training and structures are in place to prevent such risks manifesting.

The importance of recovery criteria is again highlighted when considering how to minimise the risk of relapse particularly amongst clinicians. This is contrasted by the perspective of people with lived experience who generally felt they ought to manage their own perception of recovery, and potential for relapse alongside choosing to be a peer worker:

> *"Often eating disorders are a lifelong journey, and peer support workers go in and out of their own relapsing. It can be boundary-crossing, triggering, and difficult for our clients to see the peer support workers go up and down in weight."*
>
> Clinician

So too is training regarding how and what to share about one's own experience, as well as boundary setting around that relationship. This can also be managed through organisational infrastructure and policies that manage contact between the peer worker and the people they're working with, including at the 'end' of the relationship, as well as supervision, but there are always risks or issues that may arise regardless. For example:

> *"They [peer support group facilitators] were very clear about the rules, but you can't completely control it [triggering content], and the nature of an eating disorder is that it will latch on to any comment and find a way to manifest into unhelpful behaviour…"*
>
> Recipient of peer work, lived experience of an eating disorder

> *"The other thing you have to be careful of is crossing over – mission drift. When you cross over into a therapist's territory or a dietician's territory. You have to have some paperwork that explains to the client: I'm not a therapist, I'm not a dietician, I'm not going to give you a meal plan, I can't prescribe that, I can't treat your psychological disorders. I'm going to work with you specifically behaviourally and I'm going to work with your treatment team and they'll have goals for you and I'll help you follow through with those goals. And they can also set up goals too, as long as they do it in conjunction with the treatment team and the treatment team is OK with it. So, you're really clear about not going into that territory."*
>
> Industry stakeholder - international

As mentioned previously, one clinician who had many reservations about the use of peer work in the eating disorder space, gave two examples where she had observed a detrimental impact on her clients as a result of peer workers using inappropriate strategies and over-stepping the boundaries of the role and their expertise, as outlined below:

"...these peer support workers [who provided meal support] had their one model about how they got well and that's what they used with my client, which was totally inappropriate for my client, and that was all they could offer and do. So then my client had a failed treatment episode..."

"And what I've got happening with this client is that she's forcing my client's narratives...and there's quite a lot of trauma in my client's narratives...into her narrative, and her version of how this works, without any background or clinical training of what really does work. And it has often triggered my client, sent my client on a spin, in a way that I'm cleaning up for hours."

Clinician

Also, in relation to the setting of appropriate boundaries, the potential for a person's experience with an eating disorder to become dependent on a peer worker was raised as a potential risk. This risk needs to be managed, for example by limiting the frequency of contact and/or the duration of peer relationships/programs.

In terms of matching a peer worker with the person accessing peer work, there was agreement that finding a suitable match was important to facilitate the kind of connection and shared experience that makes peer work unique. Some felt that diagnosis was a key factor for an effective match, so that the peer worker would be able to draw from experiences that were like those of the person they were supporting. Specifically, some mentioned finding it more difficult to directly relate to someone with binge-eating disorder if they themselves had experienced anorexia nervosa. Others felt this wasn't essential, as a peer worker can empathise with, for example, the compulsive nature of an eating disorder, regardless of the specific diagnosis.

A range of additional factors such as gender, age, whether a person had been hospitalised with an eating disorder, LGBTIQA+ identity, and the age of family the member being cared for (in case of carer-to-carer peer work), were also mentioned as useful for matching purposes. So too were personality traits, which were harder to define and more reliant on subjective assessment. All agreed that both parties must feel a sense of authentic connection and that this could be hard to predict on paper, so in an ideal world there would be a large enough 'supply' of peer workers to allow people accessing support to be re-matched if necessary, as well as to provide initial matches based on as many of the factors (e.g. as listed above) as possible. Stakeholders also advocated for the expansion of eating disorder peer work to facilitate appropriate support a broader range of people, such as parents of adults with an eating disorder, grandparents, or siblings for example - one peer worker described siblings as "the forgotten victims of an eating disorder".

"She [patient] had two mentors. One was a person younger than her and it wasn't a good match. And then she found someone who's bit older than her who had similar values... and she was able to talk about some things that had helped to be a mentor and that really started to shift my patient in trying some of those things."

Clinician

"It's done through a kind of a case-by-case application matching process. So, we look at each application of what someone is looking for. We try to find a mentor that needs most of those things and then we match them up. I would say we pay attention to time zones, to type of diagnosis, gender orientation, religious background. We try our best to accommodate all those things and sometimes it doesn't work out... so we have to rematch."

Industry stakeholder – international

In order to mitigate against the potential risks of peer work in the eating disorder space in particular, many participants in this study felt that greater regulation and oversight is likely required, for example this might potentially include mandatory supervision requirements, or nationally accredited training/roles (potentially in a tiered system, appropriate to the specific peer role – e.g., with more stringent training requirements for those providing practical support). At the same time, it was noted by some that care must be taken not to 'over-regulate' to the point where the authenticity and flexibility of peer work might be lost.

6. Summary of findings and future directions

6.1 Overview of findings

This research sought answers to four key questions:

1. What are the key benefits of establishing and integrating an eating disorder-focused peer workforce in Australia?
2. What is the pathway for operationalising this need, from development to implementation?
3. What are the key factors influencing success of the peer work model?
4. How do we properly safeguard the peer workers, as well as the people they support?

The outcomes of this research have provided insight on the benefits of eating disorder-focused peer work and given an indication as to the key factors influencing success and how we might safeguard peer workers. However, further work is required to build a formalised evidence base around some of these indications and gain greater clarity at a more granular level (i.e., exactly what training is required to minimise risk of relapse or how to define recovery) to, in turn, robustly develop the pathway for operationalising the need for an eating-disorder focused peer workforce (i.e., how that training should be facilitated and by whom).

Regarding benefits, there is a consensus that peer work in eating disorders is an important adjunct to the clinical care model but should be positioned as distinct. It is understood to offer hope and motivation that recovery is possible – at all stages of the recovery pathway. This is in part because some people may have had negative experiences with clinicians. In this situation the empathy of peer workers can help reduce feelings of isolation, stigma, and shame, thereby supporting the person experiencing an eating disorder to more easily embrace and persist with a recovery mindset.

However, there are several challenges and unmet needs within peer work that relate back to lack of funding and infrastructure, and which are relevant for the question of how to operationalise the need. For example, clarity is required about how and when peer work should be optimally positioned on the recovery pathway and within the care model – and the appropriate outcome indicators to measure success. This will be essential for achieving buy-in from and engagement with clinicians, without which awareness and access to peer work will remain low.

In addition, peer work in eating disorders is highly fragmented with a lack of consistency and centralisation about how this should be delivered, including how the workforce should be recruited, remunerated, trained, and supervised. There are aspects of all parts of this process that are performing well, but these need to be standardised to enable expansion of the workforce and to validate it across the sector. Importantly, interviews with international stakeholders did not reveal a gold standard/best practice example that can be leveraged here in Australia not least because of limited funding but also due to differences in the health care system.

In summary, the outcomes of this research are relatively well aligned with the previous work on this subject completed by both the NEDC and the NMHC. In essence, it further adds to the compelling narrative regarding the value of peer work in eating disorders and the rationale for increased investment and expansion of the peer workforce. Based on these findings considerations for the development of a successful and expanded peer workforce in eating disorders are presented below, together with a discussion of policy and implementation implications.

6.2   Creating the optimal conditions for eating disorder peer work

The research presented in this report has consistently revealed similar themes of unmet needs that limit the current peer workforce, at a top-down contextual and environmental level, at a service delivery and day-to-day practice level. Generally, these centre around the core issue of infrastructure, with ramifications for education and engagement. This issue needs to be addressed to successfully expand the workforce.

The unmet needs that have been identified and discussed in this report are underpinned by a lack of policy direction stipulating a specialised focus on peer work in eating disorders as separate to that which occurs in the care of other mental illnesses. Consequently, adequate funding to build and facilitate the infrastructure, education and engagement required to deliver on this service is currently lacking.

To facilitate future expansion of eating disorder peer work, as an adjunct to clinical care, and improved outcomes the following areas should be addressed:

1. To expand the delivery of eating disorder peer work, the existing infrastructure must first expand, beginning with standardisation and regulation of the service intervention. Most importantly, a consensus on the practice framework i.e., formalisation of types of peer work, must be reached.

2. Increased funding is required not only to expand the eating disorder peer workforce, but to optimise current service delivery within the existing infrastructure i.e., in ensuring access to care.

3. For any progress to be made either on expansion or in optimising current delivery, further research is essential. This is required both to unpack the needs and nuances of eating disorder peer work more deeply on specific elements such as a recovery definition, and to build a robust evidence-base to support and inform delivery of an expanded peer workforce.

6.2.1   Expansion of infrastructure is required to expand the eating disorder peer workforce

There is a clear need for infrastructure in the current peer workforce for several reasons. Most importantly, this is due to the need for an overarching standardised framework for care that aligns with the NMHC peer work guidelines, but which is sensitive to the unique nature of eating disorders. Moreover, this framework must be combined with a centralised regulatory body to ensure quality standards of care are consistently delivered.

As described previously, whilst there are four main types of peer work, these vary considerably in how they are implemented and delivered depending on the care provider. This makes it difficult to adequately position the peer worker in the care paradigm because training, the types of services provided, and supervision of peer workers differs between providers. Moreover, peer work in eating disorders is not closely regulated and formal qualifications are not a standard pre-requisite to peer work. To an extent, this then undermines the value proposition to clinicians because there is no standardisation and consistency of care.

As a result, clinician support for peer work in future (thus, possibly access too through lack of referrals) could be limited due to a lack of advocacy. Moreover, it is more difficult to ensure that the wellbeing of the peer worker is protected because there is no centralised framework for service delivery, which in turn can impact outcomes for the person accessing care and further undermines the perceived value of peer work.

Ultimately the critical issue is that provision of peer work is not standardised in the care model – rather, it is perceived as a nice to have, available to only a few, and lacks the overarching policy direction for a focus on the eating disorder peer workforce as distinct to others across mental health. This is a necessary change and precursor to resolving the underlying issue of a lack of funding.

A lack of a strategic view and practice framework is restricting service delivery

A future facing approach – in terms of expanding the eating disorder peer workforce – is essential. Several inconsistencies in the current delivery of peer work such as training, recruitment and remuneration have also been identified.

This highlights that a critical first step regarding infrastructure is the need to agree upon a framework for what peer work should look like. Here, it is recommended this is delineated by the level of involvement in recovery and care, which is in turn related to the level of training someone has undertaken.

For example:

- **Integrated to the care team and ongoing according to need:**
  - Akin to the one-to-one coaching already provided, which can occur in both residential or inpatient settings as well as in outpatient or community, and applicable at all stages of the recovery journey. Based on this research it is recommended that these peer workers must have undertaken accredited training such as the Certificate IV in Peer Work (possibly with the addition of an eating disorder specific module), the Carolyn Costin training, another tertiary qualification in mental health, or a new training program (which would need to be developed).

- **Community based mentoring with a fixed duration:**
  - Like one-to-one mentoring, wherein peer work must occur in outpatient or community settings and for a fixed duration, and at a point when the person experiencing the eating disorder is seeking final resolution of specific goals to facilitate 'healthy' living. Peer workers in this role may only need mid-level training (which, again, would need to be developed), with this type of peer work is provided on a voluntary or casual employment basis.

Although there are likely significantly more nuances to be mindful of, this type of approach will then facilitate the standardisation of e.g., training and qualifications, whilst also maintaining the specificity required for how peer work varies in different contexts. With regard to training and qualifications, as indicated in Section 5.5.2, while there is agreement on some core principles, further work is needed (including, as noted elsewhere, evaluation) to develop the features of standardised training requirements appropriate to different settings and types of peer work.

Policy implications

As has been extensively discussed, the current context strongly limits the scope and likely efficacy of peer work within eating disorders in Australia. More precisely, whilst the overarching policy direction supports a focus and investment in peer work in mental health generally (although it's yet to be determined how this shall be funded and realised) there is a gap when it comes to eating disorders. There are four key areas to address to start building the required infrastructure:

- Establishment or attribution of responsibility to a single centralised coordinating body to oversee, regulate and advocate for eating disorder peer work

- Allocation of budget spend, ideally through this centralised body, to be distributed at a state and jurisdictional level as appropriate and ensure parity of access across public and private healthcare via for example Medicare or an NDIS style system

- Development of a clear strategic direction for the expansion and implementation of peer work in eating disorders

- Support for peer work in eating disorders as a form of recognised care manifest in the formalisation of accreditation and qualifications, and appropriate remuneration.

The above is not necessarily an exhaustive list – rather, these are highlighted as priority areas for attention in the short-medium term.

6.2.2 Increased funding is required to optimise what infrastructure does exist

To establish and support the implementation of an eating disorder peer workforce infrastructure, it goes without saying that sufficient funding is necessary to realise the need. At present, a lack of funding not only restricts expansion of the eating disorder peer workforce through expanded infrastructure, but it also restricts optimal delivery of the current service – again through challenges with infrastructure. More specifically:

Access to peer work is limited or restricted due to funding

There is a need for increased funding to increase access to peer work services, particularly that of one-to-one coaching, which is mainly an out-of-pocket expense at present, precluding many from benefiting.

- In short, many simply couldn't afford to access peer work if more public services are not made available and/ or if peer work is not government funded, especially in the context of a person experiencing an eating disorder requiring multidisciplinary care and several clinicians.

- An indirect benefit of increasing access, if we look at the international perspective, is that peer work can help offset some of the pressure on more traditional treatment approaches and in Australia, helps to manage waiting lists in some cases.

Organisation-led and delivered programs are for a fixed duration.

- According to many of those interviewed, this is the recommended approach because it minimises the risk of dependency in the relationship.

- However, it was also reported that flexibility around the duration of care be considered in some circumstances. For example, one peer worker discussed how it might take someone 4 months to share fully. That said, it could potentially be detrimental to have a peer work relationship that far outlasts a therapeutic relationship as it may place a higher level of responsibility on the peer worker.

- Access to supervision particularly in a one-to-one context is not usually free, except when provided in an established service setting either directly or in the context of an Employee Assistance Program. Other services to support peer worker mental health and wellbeing such as appointments with a clinical psychologist also come as an additional out of pocket cost.

- Whilst this is an area that state-based, publicly funded, organisations deliver on, this challenge could be addressed through the introduction of a centralised regulatory body and standardisation of the peer framework. Again, this is only possible through increased funding to ensure these resources are available.

Access to peer work is limited or restricted due to low levels of awareness

There are low levels of awareness of the existence, value, and possibilities of peer work in eating disorders and clinicians.

- This is in part because it is an emerging field, in part because the workforce and service delivery are not as expansive as they could be, and partly (and because of the current size of the workforce) because it is not broadly advocated for at this time.

- Investment is therefore required not only to expand eating disorder peer work, as has been discussed, but importantly to engage clinicians to advocate for the need for increased funding and in turn increased usage to justify that funding.

- Access to peer work amongst people experiencing an eating disorder appears to occur somewhat by chance meaning it is likely that many who would benefit who aren't currently able to.

- This may be possibly related to low levels of awareness about the existence of and potential benefits of peer work programs and more generally but particularly among treating clinicians and health professionals. Consequently, it seems access to programs seems to happen somewhat by chance (people aren't generally googling 'peer work', for example).

- Again, due to a lack of a national approach and clear policy direction, the necessary education and engagement work hasn't (yet) been carried out amongst the target audience

- One person who accessed peer work suggested a way to improve access could be that we *"almost need a centralised place where peer workers are, rather than there being an onus on individuals to do self-promotion."*

Where there is awareness of eating disorder peer work, demand outweighs supply

In alignment with demand for eating disorder services generally in Australia, a key unmet need reported particularly by industry leaders is the need for an increased number of peer workers at all levels – providing all types of care – which organisations cannot currently afford.

Even more importantly, there is a need to facilitate peer work that is more tailored to support, for example, people who are not only experiencing an eating disorder but also struggling with gender identity issues. Equally, there is a need to ensure there are sufficient peer workers to support the many types of eating disorders that people experience. The same is true for parents with adult children experiencing an eating disorder where currently much of the focus is on those in paediatric care.

6.2.3 To expand the eating disorder peer workforce, further research is essential

A critical need that has been highlighted throughout this research, as well as in the literature review conducted by the NEDC, is that of a robust and expansive evidence base for how and why peer work should be integrated into the eating disorder care model (to maximise the efficacy and minimise the risks). It is therefore proposed that:

- Public spend on research conducted in academic institutions and state organisations in this area is increased to facilitate a full program of work, for example through an organisation like the new National Eating Disorder Research Centre. The establishment of a dedicated research stream could explore the factors of influence of key outcome indicators and inform the development of a comprehensive practice framework to underpin the expansion and implementation of peer work in eating disorders.

- Focus areas for research could include arriving at an appropriate definition and threshold for recovery that minimises the risk of relapse, exploration of drivers and barriers to engagement with peer work amongst clinicians and persons experiencing eating disorders including optimal referral pathways, and the development and testing of variations on the type of peer work provided, at different points on the recovery pathway, in relation to key outcome indicators.

6.2.4 Conclusion

In conclusion, the outcomes of this research support and align with existing research that has been completed in this field together with the recommendations from the Lived Experience (Peer) Workforce Guidelines developed by the National Mental Health Commission.

The goal for this research was not to arrive at a clear strategy for precisely how to expand the eating disorder peer workforce. Rather, it was to leverage extensive primary data to establish if these support existing findings and address knowledge gaps. Ultimately, further work is required, and these insights have provided some direction on what to prioritise. But what is evident and critical to reinforce, is that peer work in eating disorders is felt to be mutually beneficial to those with lived experience, and those who are currently experiencing an eating disorder. This means it has the potential to not only improve recovery outcomes at an individual level but to reduce demand on eating disorder services overall.

Acknowledgements

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