Butterfly

Lived experience perspectives on Eating Disorders Peer Work

An exploration of themes

Acknowledgment of Lived Experience:

As an organisation that works with people affected by eating disorders, including families and carers, we recognise the value of lived experience as a form of knowledge and as a force for positive change. We would like to acknowledge and thank all people with lived experience who participated in the lived experience survey, consultations, focus groups, and co-design groups to contribute to the Guidelines.

Several themes emerged during the course of the multistage lived experience engagement process undertaken for the Eating Disorders Peer Workforce Guidelines. The themes summarised in this article were raised by multiple groups of stakeholders, including peer workers, people with lived experience, carers, and other stakeholders involved within the eating disorder sector. Short summaries of these themes were included in the 'Listening to Lived Experience' sections within the Eating Disorder Peer Workforce Guidelines (Utpala, Squire, & Farrar-Rabbidge, 2023). This article extends upon the themes explored in the Guidelines.

For people with lived experience, eating disorders peer work is unique compared to other forms of peer work (Guidelines pages 10, 11, 20, 29).

Throughout the lived experience consultations, the questions 'Can mental health peer workers or general peer workers become eating disorder peer workers? Why or why not? What is learnable and what is not learnable?" were discussed. While it was agreed that eating disorder peer work can be underpinned by the values, practices, and standards of general peer work, people with lived experience considered it to be a specialised field of peer work, due to the added complexity of supporting people experiencing an eating disorder. Through an analysis of all the lived experience consultations, three areas were identified as being unique to eating disorder peer work which included:

- Lived experience of an eating disorder, body image concerns, and/or caring for someone with an eating disorder and other experiential expertise intersecting with eating disorders
- Specialised knowledge and expertise in eating disorders and recovery
- Knowledge and skills of peer work best practice in supporting someone receiving care for an eating disorder.

For eating disorder peer workers, knowledge of eating disorders will be mostly non-clinical and may include the various types of eating disorder behaviour and experiences, an understanding of the day-to-day challenges an individual experiences, an understanding of the diversity of eating disorder experiences and the intersection of eating disorders with other experiences (e.g., trauma), the complexity of the illness and the risk of relapse, understanding a person's distress around eating and their relationship to food, and the common symptoms, behaviours, self-talk, and thoughts that a person with an eating disorder can experience. Knowledge of the physical nature of eating disorders and common symptoms, mechanisms, and manifestations of the illness are all areas of knowledge identified by people with lived experience. A person working with a person experiencing an eating disorder might have high level knowledge of the services, systems, eating disorder treatments, and therapies provided as a part of a service and the challenges a person with an eating disorder, and their family, could experience when navigating treatment and working with differing health professionals.

There is limited consensus on what it means to be an 'eating disorders peer worker' (Guidelines pages 18, 22, 23)

In addition, individual perspectives on 'what it means to be an eating disorder peer worker' led to questions throughout the consultations such as: "How do we define eating disorder peer work?"; "Who should be an eating disorder peer worker?"; and "What distinguishes the peer worker from the rest of the disciplines?". Without a uniform definition, people with lived experience said that it could be difficult to scope peer work and outline best practice, without consensus on what it means to be a peer worker.

"We need to figure out collectively in the eating disorder industry regarding what does it mean to be a peer worker or what does that role include" (Peer worker).

I was confused about the lived experience area because I was like well how are they a peer? They are not, what makes them a peer? But if you view peer work as just a role then anyone can be a peer worker" (Person who had accessed peer work).

The lived experience engagement process involved holding space for all the varying differences in peer worker roles, and perspectives around what it means to be a peer worker while finding agreement on beliefs, values, and enabling practices that could guide the eating disorder peer workforce. Peer Workers, Peer Mentors, Peer Coaches, Eating Disorder Coaches, Carer Peer Workers and Mentors, and people with lived experience working in clinical roles, all shared a common goal of improving the eating disorders peer workforce.

Lived experience of an eating disorder or caring for someone with an eating disorder are central elements to eating disorder peer work (Guidelines pages 11, 12, 29, 30, 46, 47)

A concept discussed throughout the engagement process by people with lived experience was: "Does an eating disorder peer worker need to have a lived experience of an eating disorder?"; and "Do they need to have had similar experiences to that of a peer work participant to be considered an effective peer worker in the field?". Consultation participants shared that it is highly preferable that a peer worker have a direct lived experience of an eating disorder or lived experience as a carer if in the role of carer peer worker.

A peer worker who has lived through their own experience of an eating disorder can relate to a peer work participant through shared learnings and experiences which can then help a peer worker bring understanding, empathy, validation, and hope for recovery to a participant while reducing feelings of shame and isolation. While personal lived experience of an eating disorder was discussed significantly, other forms of experiential knowledge were important such as carer lived experience, experiences of navigating recovery from an eating disorder, lived experience of treatment from an eating disorder, and navigating the system of care, or a particular service setting (such as inpatient treatment), and experiences of stigma and shame from an eating disorder. Peer workers are more likely to understand the unique thoughts, behaviours, and fears that appear in an eating disorder such as fear of mealtimes or the resistance to recovery. People with lived experience can also speak the language of eating disorders, from that of other experts, clinicians, or people with mental ill-health, which might bridge the gap between a treatment team and the person receiving care.

"I found it easier when I was accessing peer work for my worker to have had lived experience and it was a lot more easier and comfortable to talk about things" (Person who accessed peer work).

While participants agreed that having someone with lived experience of an eating disorder is the preference, they believed that depending on the service, context, and requirements of the peer work participant, a general mental health peer worker should not be precluded from supporting someone with an eating disorder. The discussion of "What lived experience is considered valid to eating disorder peer work and what experiences are in scope?" began a discussion around holding space for the diversity of experiences of eating disorders, which commonly co-occur with other conditions. Those with lived experience considered intersectionality and diversity to be relevant experiences for an eating disorders peer worker but also said that these forms of knowledge could be developed and practised within peer work through connecting with others' experiences.

"With diversity, people are touching with two things because there is the ability to work with diverse people and also being diverse yourself – in most centres might only have one or two peer workers and you are not going to cover every variation and experience no matter who you get. I think it's important for sites to try and get people from different backgrounds but unfortunately, you won't get everyone's experiences in peer work and I think it's unrealistic for peer workers to connect on every point with the person they are working with so it's more about that ability to work with people from different backgrounds and draw from your own lived experience and also know where your lived experience stops." (Peer Work Coordinator and Supervisor).

Perspectives on the questions of "Would you rather have an eating disorder peer worker who has lived experience of an eating disorder but provides low-quality care? Or a general mental health peer worker who follows best practice and brings hope to their client?" were shared within a consultation. Peer workers in regional and rural settings understood the practicality of not always having access to specialised or suitable peer workers and asked, "What are important qualities in peer work and what can be translatable?". While lived experience of an eating disorder is important, how a person uses their experiences through values, training, practice, and connection with others, are qualities that should be considered. People with lived experience of an eating disorder may possess more knowledge of eating disorders and treatments but should still be expected to undergo training in peer work in order to use this knowledge safely.

"If there isn't a person with lived experience of an eating disorder then it depends what the purpose and the place of the peer worker is. When I think of my work some of what I do is more drawing on my lived experience of navigating the mental health system in general or I am being an advocate for the people I am supporting so I am using the fact that I have been through therapy and things like that, in a different context to them but using that part of my lived experience to be a support person and advocate for them even if our lived experiences might not match up entirely, so it just depends on where does that peer worker still work differently to a clinician. Is it still helpful to talk to someone who has been through those systems?" (Peer worker).

The ability to translate various experiences into lived experience expertise, communicating values such as hope, using appropriate skills, and collaborating effectively with an MDT team, can surround and strengthen a peer worker's lived experience to transform them into an effective peer worker. This process illustrates the importance of the Eating Disorders Peer Workforce Guidelines to enhance the power of the lived experience workforce and shape the workforce to the highest standard.

The concept of 'recovery' was considered more prominent within eating disorders peer work in comparison to peer work within other sectors (Guidelines pages 10, 30, 31, 32, 33).

A discussion that also arose from lived experience consultations on lived experience peer work was "How recovered does a peer worker need to be?" and "Who defines recovery?". While some individuals with lived experience strongly believed that a peer worker should model "full recovery" from an eating disorder, others believed that there should be measurements for recovery where a peer worker can effectively demonstrate a recovery-orientated approach in their work. People with lived experience involved in developing the Guidelines shared that they had encountered arbitrary beliefs about the length of time a person should be recovered, which prevented a person from entering the peer work profession or being able to access a peer worker. The two-year marker of recovery commonly used as an entrance marker into peer work was considered rigid by those with lived experience and did not match the enduring nature of some eating disorders, where relapse can occur.

"What happens when a peer worker relapses and is no longer fit to work? What protection do they have when they lose income?" (Person who accessed peer work).

Individuals who had accessed peer work felt that the current marker excluded people involved in ongoing recovery who have the skills and techniques to ongoingly manage their eating disorder. Measurements of staying well were put forward in the affinity mapping exercise. These included the ability for peer workers to share their stories and self-disclose safely, self-awareness of a peer worker, and a worker's knowledge of how and when to reach out for external support. Recovery was conceptualised as something that should be self-determined by a peer worker in balance with support and trust from the service which they are employed with.

"When we interview, we ask 'Are you confident in seeking help outside of this workplace when you need it? Are you confident in these things you have put in place for yourself? It's up to them to decide if they are recovered " (Peer Work Coordinator and Supervisor).

"...as we recognise the breadth and scope of what an eating disorder can look like and how long someone lives with it I guess that is something I think about a lot is that I would love to be working with a peer worker who is not 'recovered' in the traditional sense but is able to teach me skills, and techniques, and draw from their own lived experiences to support me in my recovery" (Person who had accessed peer work).

Accessible, skilled, supported, diverse, and accredited pathways into the Eating Disorder Peer Workforce in Australia are needed for people with lived experience and carers (Guidelines pages 15, 16, 20, 22, 23).

Rather than focusing on the journey to becoming a peer worker, people with lived experience emphasised that peer workers should be accredited based on their strengths, knowledge, skills, training, and ability to deliver the service. People with lived experience who engaged in the Guidelines development process had entered into the peer work profession through a several pathways, which enriched discussions around the competencies required to be a peer worker and how this might be acquired. During the discussion around training for peer work, questions arose such as "I am curious, can I get a show of hands who has done the Certificate (in peer work)?".

Without offering several supported pathways into peer work it was suggested that peer work could become an exclusive profession only available to peer workers who could afford specific training, which could discriminate against people with lived experience who are willing to acquire skills in workplace settings. These pathways involved letting people try peer work in a safe and controlled setting to explore whether becoming a peer worker is the right role for them.

"I do struggle with the idea of qualifications and requiring qualifications to be a peer worker as then it's starting to privilege people who have had the opportunity to get a qualification... we are turning people away if we expect people to be tertiary educated" (Peer worker).

During the affinity mapping exercise involving people with lived experience, several concepts were highlighted and themed as important competencies of being a peer worker, outside formal qualifications, including:

- Translating lived experience into lived expertise through safe sharing and language.
- The ability to communicate and articulate your role to your peer participant and others in your team.
- The ability to model recovery effectively and provide practical and hopeful tools.
- Setting boundaries and knowing what is within the scope of the peer work role.
- Working with a diversity of peer work participants.
- Building rapport and trust with others.
- Embedding trauma-informed, strengths-based, and inclusive practices.
- Collaboration and ability to work adjunct to health professionals and treatment team.

Pages 24 to 28 of the Guidelines shares the values, qualities, and competencies of eating disorder peer workers

Peer workers brought the 'peer' element into clinical spaces and navigated the spaces between being a friend and a clinician (Guidelines pages 40, 41, 44, 45)

Peer workers and those who had accessed peer work explored the question "How can we be the space between a friend and clinician?" and discussed the nuances of navigating this space. Peer workers balanced a level of professionalism with acting informally to build trust, rapport, and openness in the relationship with the people they were supporting. The balance between a friend and clinician could be achieved by factors such as organisational accountability, peer work role clarification, and the ability of a peer worker to hold professional boundaries.

The above spectrum from friend to clinician also depended on the context of the service and where peer work was included. When other staff members within multidisciplinary teams were unclear on the role and value of peer work, peer workers at times felt pressure to be the mediator between a multidisciplinary team and the person with lived experience. Peer workers shared that tensions could arise within a team when a peer worker has a closer relationship with a consumer due to the connection of lived experience. A peer worker might not feel comfortable speaking about a consumer or making decisions on behalf of the consumer with the MDT without the consumer in the room, following the principle of 'nothing about us, without us'.

"That's a really interesting balance for the need for the peer worker to be a friend to the client but needing to present professionally and with professional boundaries such as turning up at the right time and not doing something else as someone is talking and meeting emotional needs in that way but not being the psychiatrist or psychologist. That's a real challenge" (Person who had accessed peer work).

However, peer workers also saw strengths and opportunities of moving along this spectrum between friend and clinician in having space to be able to adapt to the needs of a peer work participant. One peer worker shared the experience of supporting a peer work participant with a major life event.

"I was working with a mentee and part of the multidisciplinary team was that she was working with a dietician. We had a good relationship all three of us because we were working together and my mentee's wedding was coming up. She had just been from the dieticians to say it would be really good to have some snacks available on your wedding day that are safe snacks, and we write out a list of snacks. And then as a peer worker, I went with her to the grocery store and helped her manage any triggers and make that safe space. It can be really hard to find that balance because it feels like a friendship but it is professional and has boundaries but you are connected on that level and I just remember that being something that was so empowering for the mentee to feel that 'I don't have to go through this alone' and I would love if peer work could expand more into that scope of could we be there to help them get groceries, could we be there to help them pick out an outfit for a really important event that's coming up and that could be recognised by a psychologist at a really at risk time and then a peer worker is then there to navigate that space that is outside of scope for a psychologist and dietician. It's like how can we be that space between the clinician and the friend? That could be applied in a lot of different ways" (Peer worker).

Another peer worker shared how they helped to make a clinical environment feel more comfortable for participants entering a service by sitting in on the screening assessment. This helped the participant connect with a peer worker from the beginning and created a 'lived experience friendly space' in an environment that can be clinical.

"I've been in the room listening to a few assessments as well and have been sitting there, present, telling the client about the service and it's a bit more of a connection thing. And while being in the assessment is a bit unusual, we are finding out all of this information on a person from a clinical perspective, it does help them to just have us in the room and we're there and we are with them, and we will be with them in the program" (Peer worker).

Peer work, where possible, should move away from the medical model and should follow lived experience models and evidence (Guidelines pages 30, 40).

Following on from the above, peer workers said that where possible, the practice of peer work should transition away from the medicalised model, including reducing the use of diagnostic language.

"I think it's super important in this peer workspace to move away from the medical model as well and use words that are not medicalised cause that feels very different to me from the purpose of peer work - the use of diagnostic language" (Person who had accessed peer work).

Peer drift was a common concern among peer workers and people with lived experience accessing peer work (Pages 40, 45).

The concept of 'peer drift' was raised, which can occur when clear direction, structure, and trust in the peer worker was not applied in a setting, and peer workers drifted too much into other roles and responsibilities. It was noted that peer drift isn't just about drifting toward undertaking clinical practices but also becoming too much of a friend to a participant and losing professionalism. Peer workers talked about the load of monitoring for peer drift and said that peer drift is everyone's responsibility. In one consultation, a peer work service coordinator shared that peer drift also applied to the roles of clinical staff and multidisciplinary team members drifting into adopting peer responsibilities and can occur when a service is less knowledgeable about the role of peers. A lack of diversity and distinctiveness between roles and responsibilities within a care team is needed.

"The concept of peer drift a bit, when you are pulled into other professions which is very, very common, and when I see the term assessment, clinical practices, standards, I started to think about that drifting into a more clinical role" (Peer worker and supervisor).

Organisational structure and support enabled peer workers to thrive within their roles and kept both the peer worker and peer work participant safe (Guidelines pages 32 to 45)

Through the lived experience engagement process, the interconnection between the culture and governance of peer work services, the practices of peer workers, and the experiences of a person accessing peer work were highlighted. A question that was explored in both focus groups, with peer workers, and those who had accessed peer work, was "What makes a peer worker seem confident and connected, and what actions do they take?". Within the focus groups, a theme emerged where it was found that poor organisational culture and governance affected the ability of a peer worker to deliver support confidently, which in turn affected the quality of peer support received, and vice versa. It was also highlighted that protecting and enabling peer workers within their roles was determined by organisational maturity and the embeddedness of peer workers within a service and team.

"That's up to the organisation to know why they have a peer worker and to establish that really clearly" (Person who had accessed peer work).

The structure and governance of an organisation's peer work service can greatly determine the practice of a peer worker and the experience of a person accessing peer work, both positively and negatively. Peer workers hold the power to bring about cultural change through lived experience to an organisational level, channelling ideas from the ground up into an organisation's structure and culture. Embedding peer workers into the design of a service can create a sense of equality within a multidisciplinary team, with the sharing of ideas and responsibilities. Experiences shared by focus group participants highlighted that all levels across the peer work ecosystem should align in practice for safety and accountability. For example, high level accountability structures should be carried through to individual peer workers, who are held accountable to these standards commensurate to their role. A lack of connectivity between an organisation's hierarchy might lead to risk, peer drift, negative organisational culture, and a lack of role accountability. Factors that enable peer workers to confidently deliver competent services include policies, procedures, risk management, being integrated within a care team, professional development, and supervision.

"We created a communication contract that said things like when they are available or whether they would take a call, text, email with you or whatever the communication medium would be and I think something that goes into that confidence and competence (of peer workers) is supervision and knowing that they had a level of protection around them as well" (Person who has accessed peer work).

Furthermore, having access to a variety of supervisors enabled peer workers. Clinical supervisors could be allies in promoting the inclusion of peer workers into multidisciplinary teams and educating others in clinical spaces. Peer-led and lived experience supervision helped peer workers to co-reflect on their own lived experiences alongside someone who has a shared understanding of the journey from lived experience to peer worker. It also helped peer workers visibly see opportunities for growth to move into senior peer and lived experience leadership roles.

Stigma of lived experience peer workers can occur and education of clinical workers on the value of peer work is required for cultural change (Guidelines pages 31, 32, 34, 42, 45, 46, 48, 49).

Structural, public, and self-stigma in relation to eating disorders can occur within the eating disorders peer workforce. Eating disorders peer workers or mental health peer workers working with eating disorder consumers within a non-eating disorder service may be exposed to pervasive diet culture, stigmatising beliefs on weight, and unsafe language.

"...unhelpful commentary regarding food and bodies as diet culture is pervasive and peer support workers are not immune to that" (Peer worker).

Stigma within the peer workforce can be present in several ways. In some cases, peer workers said that implicit stigma and negative biases regarding lived experience within a care team impacted a peer worker from feeling confident to share their experiences. In hierarchical care team environments involving power imbalances between clinicians and peer workers, peer workers feared that they would be seen as less 'competent' in their roles by other team members, due to their lived experiences. Some peer workers experienced self-stigma when working in certain contexts due to past negative experiences in clinical or inpatient settings.

"Feeling 'ornamental'. Lack of clarity around role structure and responsibilities. Simultaneously being treated as fragile at the same time as being expected to be an exemplary practitioner at all times. Stigma" (Peer worker).

Education on eating disorders and the value of peer work within multidisciplinary teams is therefore critical to developing a supportive workforce and workplace culture. Outside of the scope of the Guidelines, peer workers can play a role in educating others within a service and advocating for further involvement of peer workers and lived experience workers.

Peer support needs to be better represented and made accessible within the current eating disorder stepped system of care (Guidelines pages 6, 20, 46, 47)

A proportion of survey respondents with lived experience had never heard of peer work, did not know it was available, or were unaware of how to access a peer worker. People who were unable to access peer work said that as a form of care, peer work could be more effectively included in referral pathways, within treatment plans in conjunction with other forms of care, and could be better integrated into community, and step-down services.

Conclusion

This article highlights the importance of embedding lived experience expertise within projects such as the Eating Disorders Peer Workforce Guidelines to shape direction, content and recommendations. People with lived experience of an eating disorder, peer workers, peer work supervisors, and those who were unable to access peer work for support, navigated complex and enriching conversations about the workforce as part of the Guidelines development. Some of the same discussions had by professionals led to unresolved conclusions on peer work. While people with lived experience held contrasting perspectives on some aspects of peer work, they did agree on the importance of emphasising the themes set out above. It is recommended that future peer work training, frameworks, standards and services to be co-produced alongside people with lived experience.