



Equip

The Power of Mentorship:
Supercharging Support for Eating Disorder Recovery

August 27, 2024

Meet the presenters



After recovering from anorexia nervosa as a teenager, Maris is passionate about harnessing her lived experience to support others suffering from eating disorders. Maris currently serves as Equip's Director of Peer Mentorship.



JD Ouellette is an educator turned eating disorder advocate & coach after her youngest child developed anorexia in 2012 and attained full recovery through FBT. She is the Director of Lived Experience at Equip, and was formerly the Director of Mentorship.

Objectives

1

Describe the current research on mentorship and peer support as an evidence-informed practice.

2

Name 2–3 specific ways mentorship and peer support can be incorporated in eating disorder treatment.

3

Identify specific examples of how mentorship can support eating disorder recovery.

Why mentor support matters



Origins

People with lived experience in mental health have been influencing how we care for patients for centuries. It was the influence of lived experience that helped evolve the mental health world to be more humane, compassionate, and respectful towards patients

1960's

Campaigns for improved/more humane psych care grew alongside the civil rights and women's rights movement

1990's

Peer support began to emerge as a more formal, integrated role in the mental health world

Mid - late 2000's

The field of substance use begins proliferation of the peer support role into treatment programs

Peer support has been shown to be beneficial for improving health outcomes in numerous studies

Peer support is a strategy that has been widely used to improve physical, emotional and psychological health, and to promote self-management across diverse diseases and population groups

In a recent systematic review, 83% of the studies reported significant benefits of peer support in promoting behavior change to support chronic disease management



Examples of peer and family support in action

Crohn's and Colitis Foundation

Power of Two

American Diabetes Foundation

Association of Diabetes Care & Education Specialists

Cystic Fibrosis Foundation

CF Peer Connect Program, which connects both patients and family members

NAMI

peer-to-peer, family-to-family



Research

Inclusion of peer supports...

...generally, helps effectively engage people in care, instills hope and self-confidence, decreases substance use, increase self-care and quality of life across multiple domains

...decreases rehospitalization rates, reduces the length of treatment stays, and improves the cost-effectiveness of care

...helps parents collaborate more effectively with other professionals, empowers parents, decreases internalized blame, decreases isolation, increases recognition of the importance of self-care, and improves parental confidence and hope

Research


In eating disorders, the use of peers...

...is a critical component of effective eating disorder prevention programs, like the Body Project and EVERYbody Project


...leads to significantly lower dropout rates from treatment (5% vs 39%), larger decreases in depression, body dissatisfaction, binge eating days/week, and restriction day/week

The **Centers for Medicare and Medicaid Services** now recognizes peer support as an **evidence-based practice**, when conducted with proper training, care-coordination, and supervision by a mental health professional.


Peer support is effective in eating disorder treatment



Peer mentors are people who identify as being in a solid space of recovery from an eating disorder



Peer mentorship can lead to improvements in body dissatisfaction, mood, and eating disorder behaviors compared to other types of social support or no support



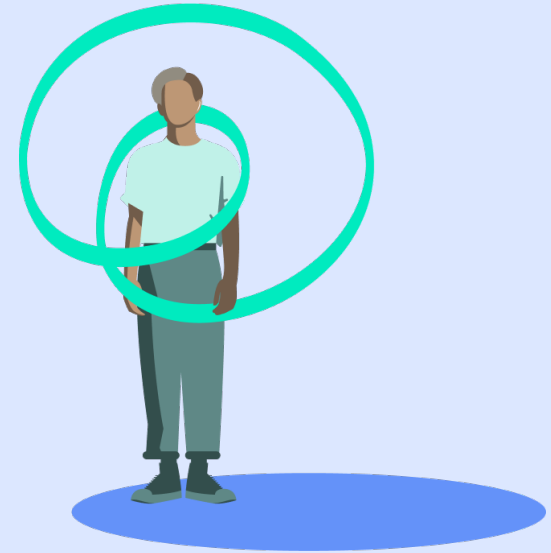
Peer mentorship can also help improve quality of life and help ED patients attend appts with treatment providers

Peer Support and Beyond: The Role of Lived Experience in a New Era of Eating Disorder Treatment (Focus 2024)

→ **“The potential impact of lived experience on every aspect of eating disorder treatment is limitless.” (Duvall, Hanson, 2024)**

→ In a recently published paper, authors Duvall and Hanson emphasize the ways in which lived experience can have a powerful impact on many facets of eating disorder treatment:

- Peer supporters working directly with individuals in treatment
- Individuals with lived experience holding positions of leadership
- Incorporating voices of lived experience into research efforts
- Highlighting the perspectives of individuals with lived experience in media publications on treatment and recovery to shift narratives

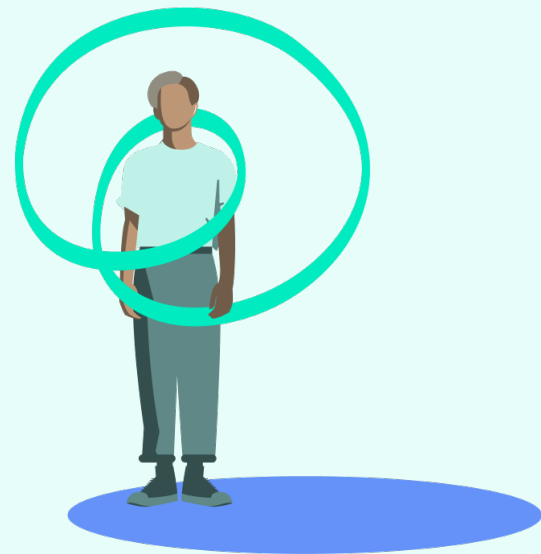


Family peer-to-peer support



Family peer-to-peer support history in youth mental health

- Family peer-to-peer support is the most fundamental element of the children's mental health family movement and has been for more than 35 years
- Kimberly Hoagwood, PhD of Columbia University suggested four core outcomes while acknowledging the absence of any good measures at this point in time.
 - Decreased isolation
 - Decreased (internalized) blame
 - Increased realization of the importance of self-care for parents
 - Increased ability to take action (through gaining knowledge and learning how to take action)



Family peer-to-peer support history in adult mental health



In a 2017 paper looking at family peer-to-peer models in mental health, Aciri et al state“ . . . it is noteworthy that client outcomes were largely positive in critical areas such as symptomatology, functioning, treatment adherence, and hospitalizations. *It may be that providing support to the entire family mobilized and strengthened the family unit, resulting in enhanced client outcomes in these critical domains . . .*”



NAMI Family-to-Family Education Program: “This study provides evidence that FTF is effective for *enhancing coping and empowerment of families of persons with mental illness, though not for reducing subjective burden. Other benefits for problem solving and reducing distress are suggested, but require replication.*”

(Aciri M, Hooley CD, Richardson N, Moaba LB. Peer Models in Mental Health for Caregivers and Families. Community Ment Health J. 2017 Feb;53(2):241-249. doi: 10.1007/s10597-016-0040-4. Epub 2016 Jun 25. PMID: 27344658; PMCID: PMC5555254.)

(Dixon LB, Lucksted A, Medoff DR, Burland J, Stewart B, Lehman AF, Fang LJ, Sturm V, Brown C, Murray-Swank A. Outcomes of a randomized study of a peer-taught Family-to-Family Education Program for mental illness. Psychiatr Serv. 2011 Jun;62(6):591-7. doi: 10.1176/ps.62.6.pss6206_0591. PMID: 21632725; PMCID: PMC4749398.)

Basic Foundations of Family Peer Support

Grounded in lived experience

Permanent relationship with a child & seeking or sought service

Experience navigating complex behavioral health systems

Communicates Active Acceptance

Ability to recognize & manage own bias

Committed to working on starting from a place of welcome for all parents

Based on strategic self-disclosure

Willing to share parts of your personal story in helping parents find their path to healing

Ability to build connections of partnership

Partnered with rather than delivered to parents

Ability to stay in a peer relationship

Support for support's sake rather than service sake

Family peer-to-peer support in eating disorders

Emerging area of interest and study

Already in place both informally and formally

Historically and informally families have supported other families through F.E.A.S.T

- The F.E.A.S.T. websites and forums may be the only resource for families in some countries, so some families rely largely or solely on information and support from families in better-resourced areas
- F.E.A.S.T. is able to draw on the wisdom and experience of many excellent clinicians who help develop resources and provide psychoeducation.

Formal programs are both relatively new and very promising

- Carer Consultation Services through The Victoria Centre for Excellence in Eating Disorders
- Eating Disorders Victoria Career Coaching Program
- Equip

Family peer-to-peer support at Equip

Extensive training

- Around all eating disorders including those outside Family Mentor (FM) direct lived experience
- Scope of Practice and Disclosure Training

Continuing education

- Both with and without full provider team

Supervision and consultation

- Weekly
- In both group and individual settings

Treatment model and patient-age-dependent practice

Family-Based Treatment and Family-Based Treatment for Transitional Age Youth Model (up to age 24)

- Robust information sharing with families
- Strong input from family members on treatment journey

Over 18 using non-FBT models

- Varied disclosure levels from provider team to family personalized to patient needs/desires
- Information from FM on how families can provide support in a nuanced versus direct way

Voices of lived experience



Maris's experience



My freshman year of high school, my parents became concerned about drastic changes in eating habits and increased exercise. Lacking education on eating disorders, they felt lost on how to address the issues they saw.

After hospitalization, my parents were tasked with feeding and weight restoration, before I felt “ready” to recover. I felt lost and alone in this process – not knowing who would understand or relate to me.

When I began talking about my story more openly, I was shocked at just how common eating disorders are – and craved hearing more stories of hope and lasting recovery.

The role of the peer mentor

Skillfulness

Trained and supported in effective listening and sharing skills

Connection

Connecting with patients outside of the ED and supporting engagement

Collaboration

Gather and share information with other providers for unified care

Hopefulness

Using intentional self-disclosure to portray realistic and hopeful examples of recovery



JD's experience



In 2011, my daughter, at the age of 17, decided to undertake a “healthy eating makeover” with her friends.

She did not have body image or self-esteem issues.

It began sensibly, but rapidly deteriorated and within 4 months she was in the emergency department with dehydration and orthostasis.

She had anosognosia (lack of insight) and was accurately reporting medical symptoms.

We were also seeing a pediatrician and GI to identify the cause.

The role of the family mentor

Warmth

Validating and being a listening ear to families who are navigating treatment

Communication

Connecting with other providers to bring forward family questions or challenges and identify solutions

Practical Support

Sharing ideas and advice from a space of lived experience

Group Support

Bringing together multiple families to normalize challenges and provide hope



Benefits to clinicians



The role of the therapist

Healing

Through therapeutic assessment and continued processing, providers seek to increase insight and motivation in order to overcome behavioral and cognitive barriers to recovery, while also remaining mindful of comorbidities and engaging in any necessary interventions

Empowerment

Empowers patients and families to understand their own/their loved ones needs, build confidence, overcome fears, and set boundaries to find lasting recovery



Expertise

Combined clinical experience and education provides guidance and informs treatment goals and expectations

Accountability

Weekly sessions allow for follow up and discussion about treatment goals and obstacles

Filling the gap: patients and supports

Mentorship offers a space for supports and patients to receive guidance so that clinical sessions can remain focused on ED symptoms and behaviors

The mentorship relationship provides a space for those receiving or delivering care to feel more holistically seen and heard

Mentorship can feel like a space with less expectation and judgement, in that it is a space where the patient or support determines what their need is in the moment

Mentors are true experts in the day to day of ED life

Mentorship can help with “individual skill building” requests while doing treatment

Mentorship offers a reprieve from the more clinical appointments. Some of these sessions, for example, can look like engaging in an activity together, discussing self care habits, or providing a listening ear when patients or families have had a stressful week.

Filling the gap: other providers

Allowing for a more thorough understanding of what can happen in the home (behaving outside values behaviors)

Providing greater context and thus empathy for stressors and struggles for families around refeeding, behavior interruption, sibling impact, schooling decisions

Insight into logistical challenges related to food preparation, food and financial insecurity

Understanding how families define recovery, which can differ from clinical definitions.

Patients are more engaged and motivated in other sessions



The full experience

The clinical relationship:

Focus on the eating disorder

Goal-centered

May or may not include self-disclosure in the best interest of patient care

Advocate for treatment expectations

Viewed as the “expert”

Environment to process built on treatment trajectory

Embody education



The mentor relationship:

Focus can be on a variety of subjects

Patient/Support-centered

Includes self-disclosure in the best interest of patient care

Advocate for patient experience

Viewed as a “peer”

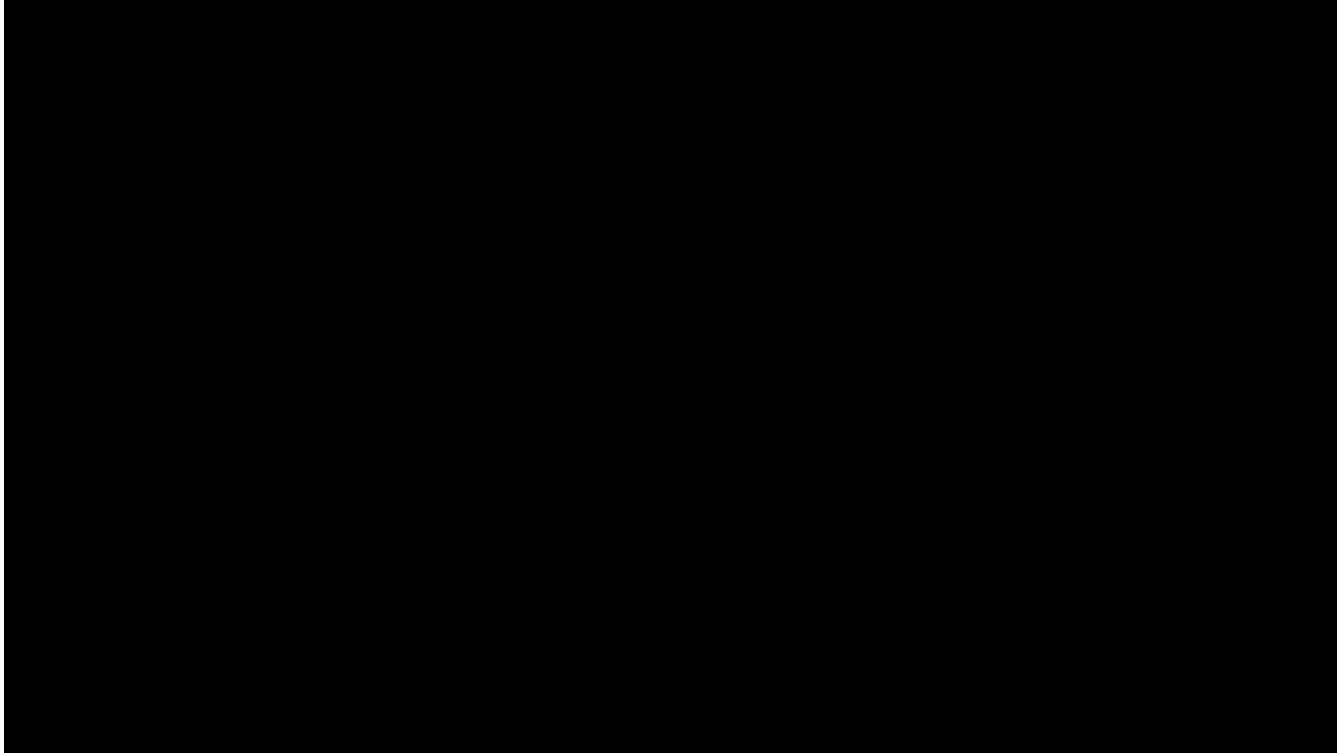
Environment to process built on mutual understanding

Embody hope

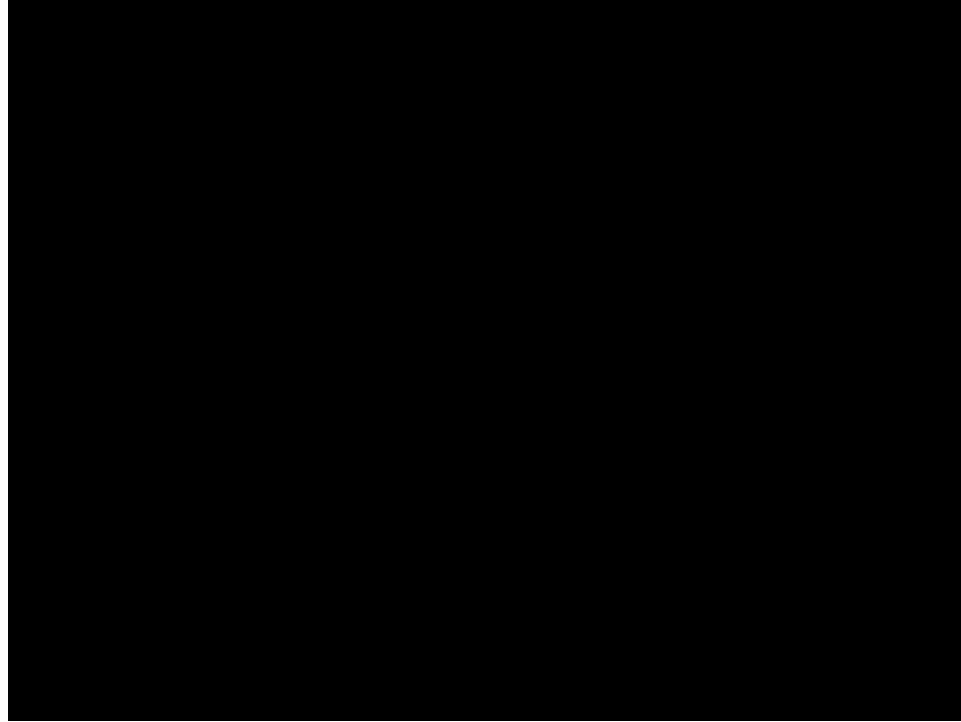
Mentorship in action



Family mentor role play example



Peer mentor role play example



Ella*, cis-gender young woman, 19, AN-R



- Lived with parents and siblings in the midwest
- Was diagnosed with anorexia as a freshman in high school
- Received treatment at residential and partial hospitalization levels of care
- In 5 years she had not restored even to her 14-year old weight and continued to struggle

Ella returned home from college when the pandemic hit and made great strides almost immediately. What was different this time?

With Equip, all family members could participate in virtual sessions, get specific training and support, and visualize full recovery. Ella's weight gain began almost immediately once the family accessed Equip's support and skills training, and they were buoyed by both hope and certainty that lasting recovery was attainable. After years of no gain, they achieved the target weight in just a few months and the family was able to collaborate with their team to map out a path to full recovery.

Comments about mentorship



Peer mentorship proved to be invaluable to our family. Lisa, our wonderful family mentor validated me and understood when no one else around me truly did. She also helped align our direction with FBT as a couple, unifying us in the fight to get our daughter well.



My daughter's peer mentor was able to draw my daughter out. She helped her to see from a shared perspective that the hard things can be done. My words to my daughter had value, but the same words from the mentor landed differently.

Comments about mentorship



In recovery, Josephine* travels to see the artists she listened to with her peer mentor live in concert. She describes herself as recovered, and a more authentic version of herself.



I appreciate everything you've helped me with so much. It's meant a lot to have a mentor who's a trans adult. There is hope! I appreciate you!"

*Name changed to respect patient privacy.

In Summary

There is a current body of research detailing the power of peer mentorship and family peer-to-peer mentorship in mental health care and further research is needed

There are a wide variety of benefits to the use of lived experience mentors that are specific to eating disorder recovery

You can ensure families and patients have access to eating disorder mentorship through sharing these resources with them

- [Equip x Feast Monthly Workshop](#)
- [ANAD Peer Support Groups](#)
- [Eating Disorders Resource Center Support Groups](#)
- [F.E.A.S.T. + ANAD Caregiver and Sibling Groups](#)
- [F.E.A.S.T. Mens' Group](#)
- [F.E.A.S.T. Video Library](#)
- [The Eating Disorders Foundation](#)
- [The National Alliance for Eating Disorder Awareness](#)
- [Project Heal](#)
- [Sage and Spoon \(BIPOC group\)](#)
- [FEDUP Facebook Support Groups](#)



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Thank you!

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