Overlooked and Underserved:

Creating novel and collaborative eating disorder care models to center underserved communities

Erikka Dzirasa, MD, MPH, **DFAACAP** Chief Medical Officer

Learning objectives for this session

- Describe the ways in which eating disorders show up among different communities and the sociocultural factors that impact them.
- Explain why combining community with clinical care is a more inclusive way for people to start healing and can drive better outcomes.
- Illustrate how a trauma-informed, culturally sensitive approach can help us to reach, engage, and support diverse populations in their healing.

Too often, BIPOC, LGBTQ+, Fat, and other marginalized communities are overlooked when it comes to eating disorders.

People in larger bodies

- Only **6%** of people with EDs are **“underweight”**
- Role of medical and weight **stigma**
- Targeted by **fatphobia** and diet culture
- Reinforcement of **weight loss and dieting**
- **Increased risk** for onset of EDs
- **Delayed** diagnosis and lack of treatment

Sabrina Strings, Fearing the Black Body: The Racial Origins of Fat Phobia

Black/African/Afro-Caribbean community

- Black people are **less likely to be asked** about body image/ED behaviors
- Black people are **50% less likely** to receive and ED diagnosis or treatment
- Black teenagers are **50% more** likely to experience **bingeing/purging behaviors**
- Black teenagers engage in **muscularity-oriented eating behaviors**

Nagata JM, Murray SB, Bibbins-Domingo K, Garber AK, Mitchison D, & Griffiths S (2019). Predictors of muscularity-oriented disordered eating behaviors in US young adults: A prospective cohort study. International Journal of Eating Disorders, 52(12), 1380–1388

Latina/o/e and Hispanic community

- Hispanic individuals are **less likely to be referred** for treatment
- **BED** is the most common eating disorder among Hispanic/Latine community
- Hispanic individuals are significantly **more likely to suffer from BN**
- **Acculturative stress** increases risk for onset of EDs

Perez M, Ohrt TK, Hoek HW. Prevalence and treatment of eating disorders among Hispanics/Latino Americans in the United States. Curr Opin Psychiatry. 2016 Nov;29(6):378-82
Becker, A. E., Franko, D. L., Speck, A., & Herzog, D. B. (2003). Ethnicity and differential access to care for eating disorder symptoms. International Journal of Eating Disorders, 33(2), 205-212. doi:10.1002/eat.10129

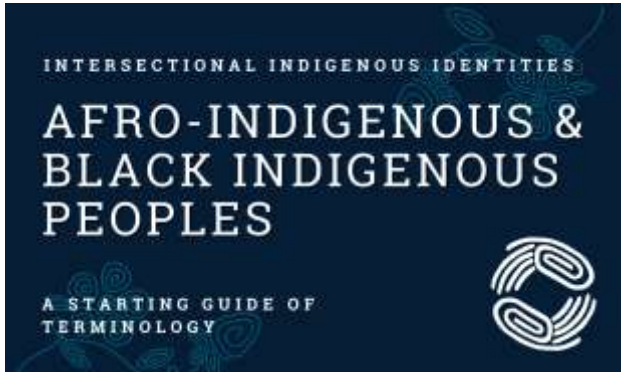
Asian American/Pacific Islander community

- Asian American college students have **higher rates of body dissatisfaction**
- Asian American college students have **higher rates of restriction, purging, muscle building and cognitive restraint** than white students
- Micro/macroaggressions and **“othering”** increase risk of EDs
- Up to **3x less likely to seek mental health treatment** due to stigma or “loss of face”
- **“Model Minority”** myth

Uri, R. C., Wu, Y., Baker, J. H., & Munn-Chernoff, M. A. (2021). Eating disorder symptoms in Asian American college students. Eating Behaviors,

Native/Indigenous community

- Native Americans/Alaska Natives are more likely to **experience binge eating**
- Native Americans are more likely to **fear losing control** over their eating
- 27% of Aboriginal people in Australia meet criteria for an eating disorder
- **Discrimination, systemic racism, and acculturative** stress are risk factors



Burt A, Mannan H, Touyz S, & Hay P (2020). Prevalence of DSM-5 diagnostic threshold eating disorders and features amongst Aboriginal and Torres Strait islander peoples (First Australians). BMC Psychiatry, 20(1), 1–8.
Striegel-Moore RH, Rosselli F, Holtzman N, Dierker L, Becker AE, & Swaney G (2011). Behavioral symptoms of eating disorders in Native Americans: Results from the add health survey wave III. International Journal of Eating Disorders, 44(6), 561–566.

LGBTQI/Nonbinary/Transgender community

- 54% of LGBT adolescents have been diagnosed with a full-syndrome eating disorder during their lifetime
- Lesbians engage in more frequent binge eating, purging, and laxative use than heterosexual people
- 82% of the lesbian participants based their self-worth upon their weight
- Gay males are more likely to suffer from clinical eating disorders/behaviors
- Transgender and gender non-conforming individuals experience higher incidences of disordered eating behaviors

Parker, L.L., Harriger, J.A. Eating disorders and disordered eating behaviors in the LGBT population: a review of the literature. *J Eat Disord* 8, 51 (2020).

Systemic barriers are keeping people from accessing lifesaving care.

We are up against a broken system

- Systemic racism
- Complex payer system
- Implicit/explicit bias
- Lack of diverse treatment providers
- Weight discrimination
- Lack of representation in research
- Shortage of healthcare professionals
- Lack of patient-centered care

https://www.theprojectheal.org/overview-of-treatment-barriers

When it comes to eating disorders, the barriers are even higher

Broader healthcare system

- Lack of screening for eating disorders
- Lack of mental health parity
- Lack of insurance coverage due to “medical instability”
- Insurance emphasis on evidence based medicine
- Lack of coordination of care/team planning

Eating disorder care

- Limited options for culturally sensitive care + diverse clinicians
- Disparities (among LGBTQ+, BIPOC communities, boys/men, older individuals)
- Emphasis on underweight population
- Focus on AN, neglecting other types of eating disorders

Beckar, A et al Int J Eat Disord. 2010 Nov 1; 43(7): 633–647.

Add personal barriers and it’s no wonder why people don’t get care

+ **Shame**, guilt, embarrassment
+ **Stigma** including within cultural context
+ **Mistrust** of the medical system
+ Previous **traumatic** experiences
+ Lack of recognition within **family, culture, and community**
+ **Financial** burden of expensive treatment
+ Clinician **bias** and negative interactions
+ Lack of **cultural sensitivity** and understanding in care

We need to think differently about care to eradicate barriers and bring people the support they deserve.

We’re integrating community and person-centered care

Care Advocate + community care

+ Members choose an Advocate for peer support, care navigation, coaching
+ 1:1 live and async support from the start of care into maintenance
+ Support groups around shared identities and experiences

Person-centered clinical care

+ Individualized care plans (ICPs)
+ Addresses co-occurring needs
+ Integrated care teams with diverse identities and modalities
+ Program includes therapy, nutrition support, psychiatry, medical care

And approach care in a way that puts members at the center

Trauma-informed

+ Ensuring physical and emotional safety
+ Building trust and rapport
+ The person has choice and a say in their care

Holistic

+ In-house care teams working together
+ Addressing underlying factors
+ Treating co-morbid conditions
+ Ongoing support

Person-centered

+ Structuring care to get to know the member
+ Understanding their experiences and goals
+ Coordinating care to work for them

Culturally sensitive

+ Vetting and hiring providers with diverse identities
+ Benchmarking and training via Violet partnership
+ DE&I workshops for full team

Addressing social determinants of health in eating disorder care

- **Healthcare Access & Quality:** Lack of insurance or underinsured
- **Neighborhood & Environment:** Housing, geography, community
- **Economic stability:** One in 10 people live in poverty, lack of employment, childcare, food insecurity
- **Education**
- **Structural/Institutional Racism**

https://health.gov/healthypeople/objectives-and-data/social-determinants-health

Holistic, inclusive care enables us to address these barriers

> *I grew up facing food insecurity so I still feel that scarcity mindset present. I am a full time student surviving on limited funds.*

> *I'm trying to get on the right track. I know I can. But I was assaulted and since things haven't been the same.*

> *I'm stressed with my job, I just moved, and my adult children have nothing to do with me...*

> *I had gastric bypass surgery this year and still struggle with disordered eating.*

- **Care Advocate and community support** to build trust and connection
- Hiring **diverse care teams** with experience in clinical and community-based settings
- Empowering care teams to use **specialized skills** and **treat members' needs holistically**
- Connecting members to **community resources** as needed

Individualized care planning to hear and center the member

- **Customized:** Each plan is designed to meet the specific needs of each member
- **Person-centered:** The member is the key architect of the plan
- **Holistic goal-setting:** The member sets healing goals that impact multiple areas of their life (8 dimensions of wellness)
- **Addressing barriers:** Care Advocates work with members to compose a plan that both acknowledges and addresses social and emotional barriers
- **Care collaboration:** The plan is shared, updated and modified by all members of the Care Team (including the member)

Bringing community and person-centered clinical care together for long-term healing.

Peer support has significant benefits in healing

- Increased engagement in care
- Greater reductions in body dissatisfaction
- Greater reduction of anxiety
- Greater reduction in depression
- Greater reduction in binge eating days/week in patients with BN/BED
- Greater reduction in restriction days/week in patients with AN

Ranzenhofer LM, Wilhelmy M, Hochschild A, Sanzone K, Walsh BT, Attia E. Peer mentorship as an adjunct intervention for the treatment of eating disorders: A pilot randomized trial. Int J Eat Disord. 2020 May;53(5):497-509. doi: 10.1002/eat.23258. Epub 2020 Mar 11. PMID: 32159243; PMCID: PMC7383944.

Building trust and connection through community care

Care advocates are members of the care team, but not therapists or clinicians...they are guides, supporters and mentors.

1:1 Support

+ Individual Care Planning
+ Peer Mentorship (Vision Alignment and Social Skill Development)
+ General Social/Emotional Support

Peer Group Support (Community Care Groups)

Care Navigation and Advocacy

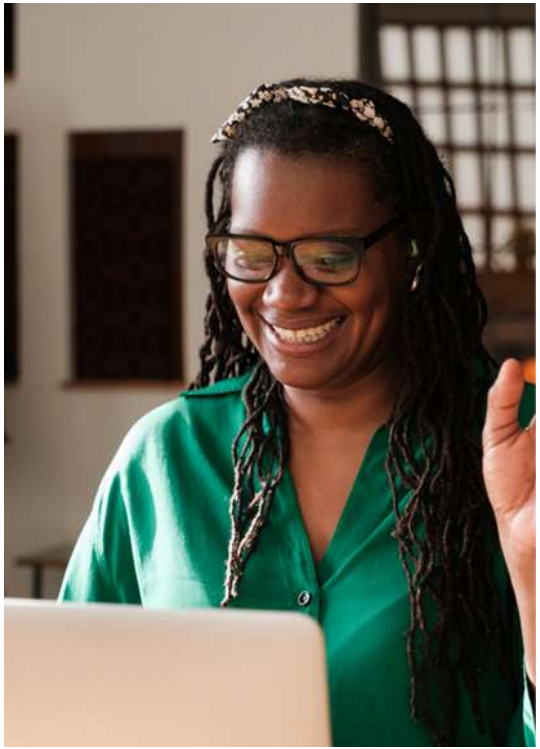
+ Care Team Meetings
+ Care Coordination
+ Care Referrals

Care Advocates work with members to have voice and agency in their care

- **Advocacy:** Ensure members have a say in their care and that their voice is heard
- **Alignment:** Provide information to ensure members understand their recommended care plan — and assist with integrating care into their goals and life
- **Accountability**: Hold the care team (including themselves) and members accountable for placing members' wellness goals at the forefront
- **Autonomy:** Assisting members in their development of the skills and tools they need to live independent and enriched lives

What we can collectively do

- **Check** your own biases
- Approach your clients with **cultural curiosity**
- **Create a space** where your client feels **heard, valued and understood**
- **Consider how systemic barriers** may have precipitated or perpetuated your client's eating disorder
- **Changing the culture** of ED diagnosis and treatment starts with YOU!



Key takeaways

- **Sociocultural factors** impact how eating disorders affect different communities
- Care that is **trauma-informed, holistic, person-centered, and culturally sensitive** is critical for supporting these communities
- **Person-centered care** acknowledges each individuals' goals, barriers, and experiences, including SDoH
- **Integrating clinical care with community support** is an effective way to address these needs and promote long-term healing

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Thank you!

Erikka Dzirasa, MD, MPH, Chief Medical Officer erikka@wearise.com