Leveraging Community Engagement to Address Behavioral Health Disparities in the Deaf Community

Melissa L. Anderson, PhD
Alexander M. Wilkins, PhD

UMass Chan MEDICAL SCHOOL

Implementation Science & Practice Advances Research Center
iSPARC
Improving Mental and Behavioral Health Services for Better Lives and Stronger Communities

DEAF YE
Center for Deaf Empowerment and Recovery

Agenda

1. Who are the U.S. Deaf Community?
2. What are common barriers to their healthcare?
3. How does our team tackle these barriers?
4. Panel discussion
5. Audience Q & A

Disclosures

We have no actual or potential conflict of interest in relation to this presentation.

Research described in this presentation was supported by the National Institute On Alcohol Abuse and Alcoholism (NIAAA) of the National Institutes of Health (NIH) under Award Numbers R34AA026929 and K23AA029466, as well as the National Institute of Deafness and Communication Disorders (NIDCD) under Award Numbers R21DC019216 and R21DC015580.

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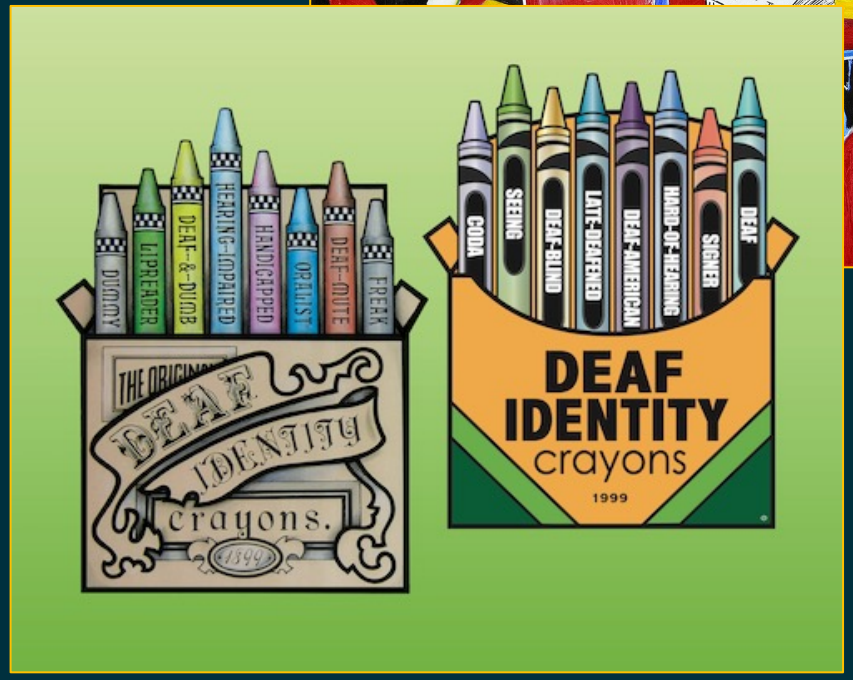
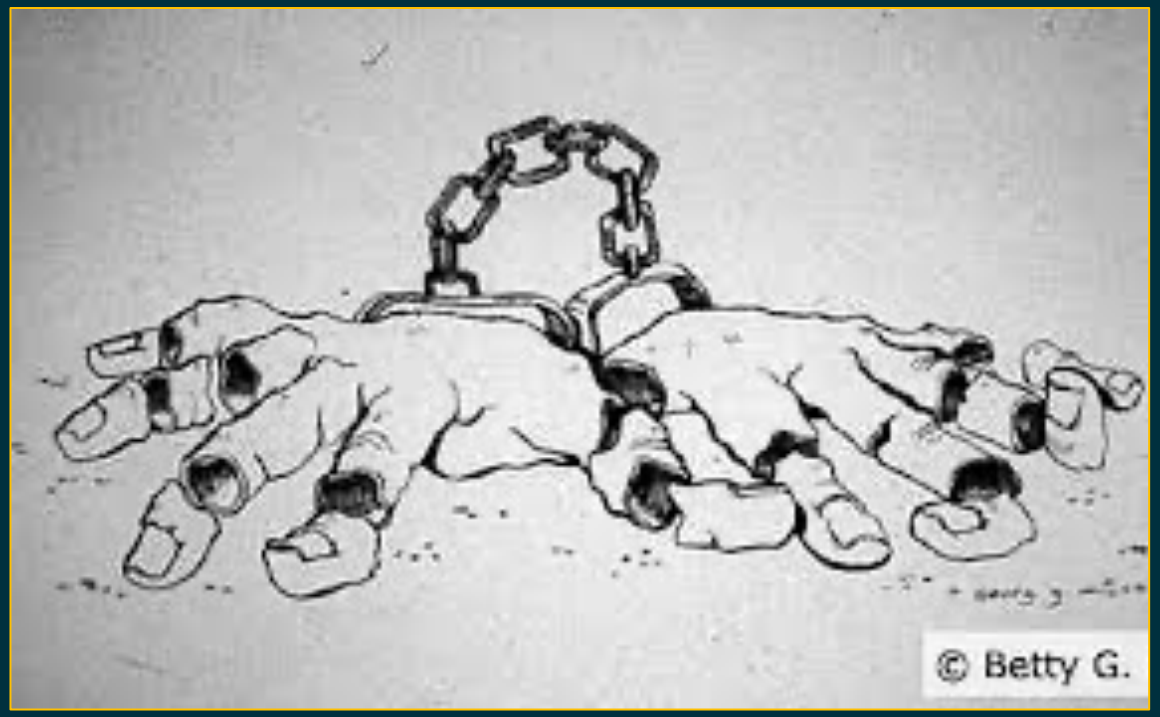
U.S. Deaf Community

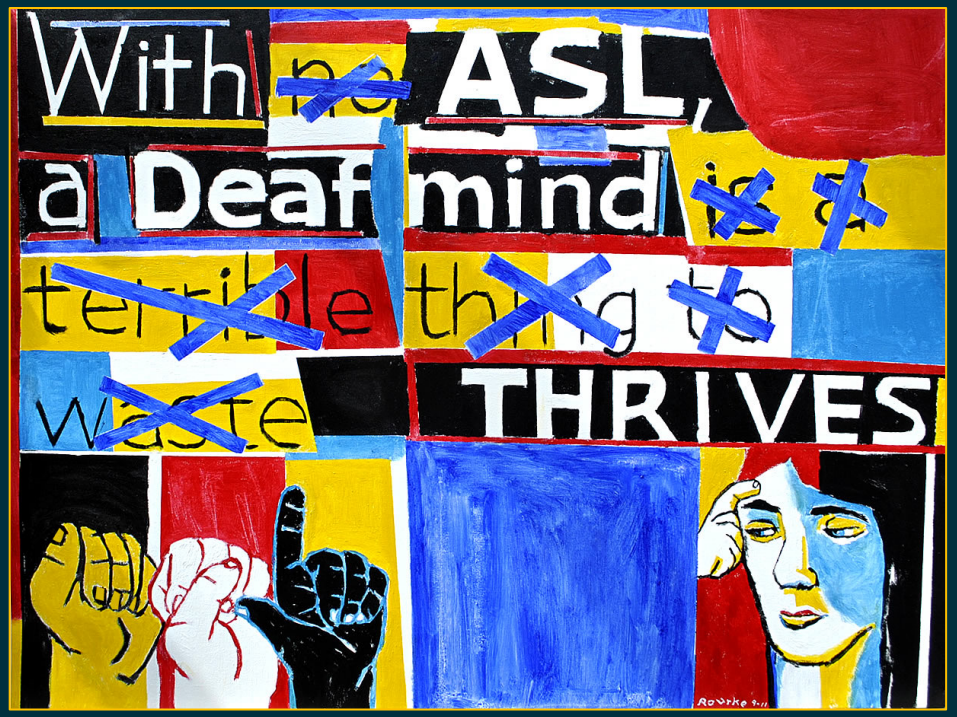
- 500,000+ individuals who communicate using American Sign Language (ASL)
- Cultural view of embracing Deafhood versus medical view of curing/fixing deafness



U.S. Deaf Community

- History of oppression within majority hearing world, especially around freedom to use ASL





Social Determinants of Health

- Compared to hearing populations, Deaf people experience higher rates of:
  - Adverse childhood experiences (ACEs)
  - Under- and unemployment
  - Public insurance or lack of insurance
  - Limited educational attainment

Behavioral Health Disparities

- Increased rates of mental health conditions and substance use disorder. Examples:
  - Mood and anxiety disorders = 2 - 2.5x the general population
  - Attempted suicide = 5x the general population
  - Trauma exposure = 2x the general population
  - Problem drinking = 3x the general population

Language

- Deaf clients' primary language = ASL
  - Limited number of ASL-fluent professionals
  - Limited access to, willingness to provide, or funds to support certified ASL interpreters
  - English (written) is acquired as a 2nd language
- Many Deaf individuals have also been impacted by early language deprivation

Health Literacy

- Many Deaf clients also present with fund of information deficits and low health literacy:
- Health-related vocabulary among Deaf ASL users parallels non-English-speaking U.S. immigrants
- “Many adults deaf since birth or early childhood do not know their own family medical history, having never overheard their hearing parents discussing this with their doctor” (Barnett et al., 2011)

Mistrust

- Most healthcare providers and researchers are hearing and, therefore, represent the majority oppressor group
- History of medical oppression has led to:
  - Increased *mistrust* and fear
  - *Reduced cooperation and collaboration* with hearing healthcare providers and clinical researchers
  - Complete *avoidance* of the healthcare system and the research world

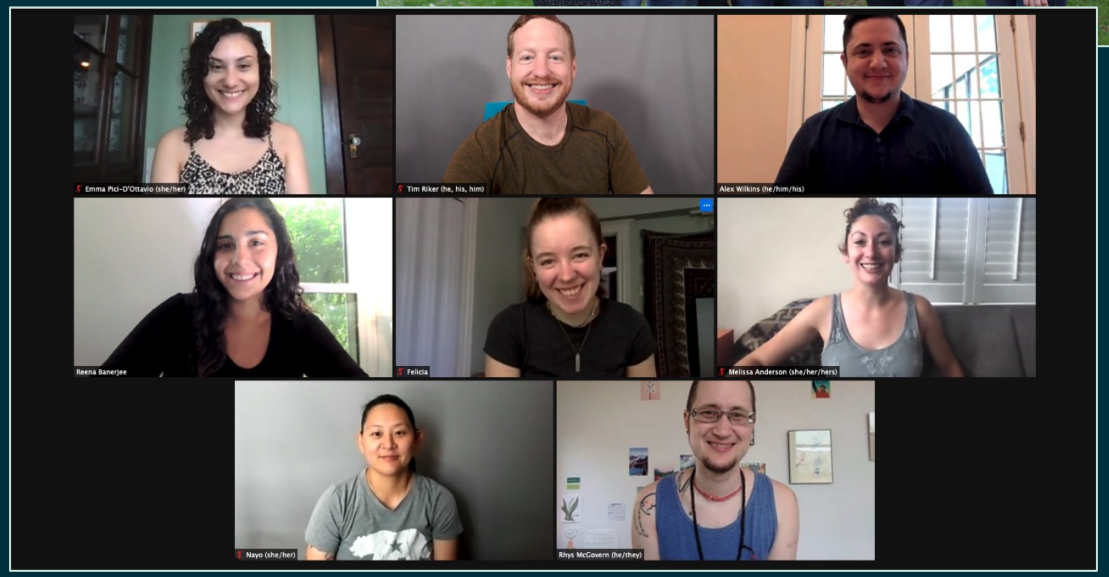
DEAF YE

Center for Deaf Empowerment and Recovery

Our mission is
to partner with the Deaf community
to develop innovative
addiction and mental health resources
that are uniquely and expertly tailored
for Deaf signing people.

Team Development

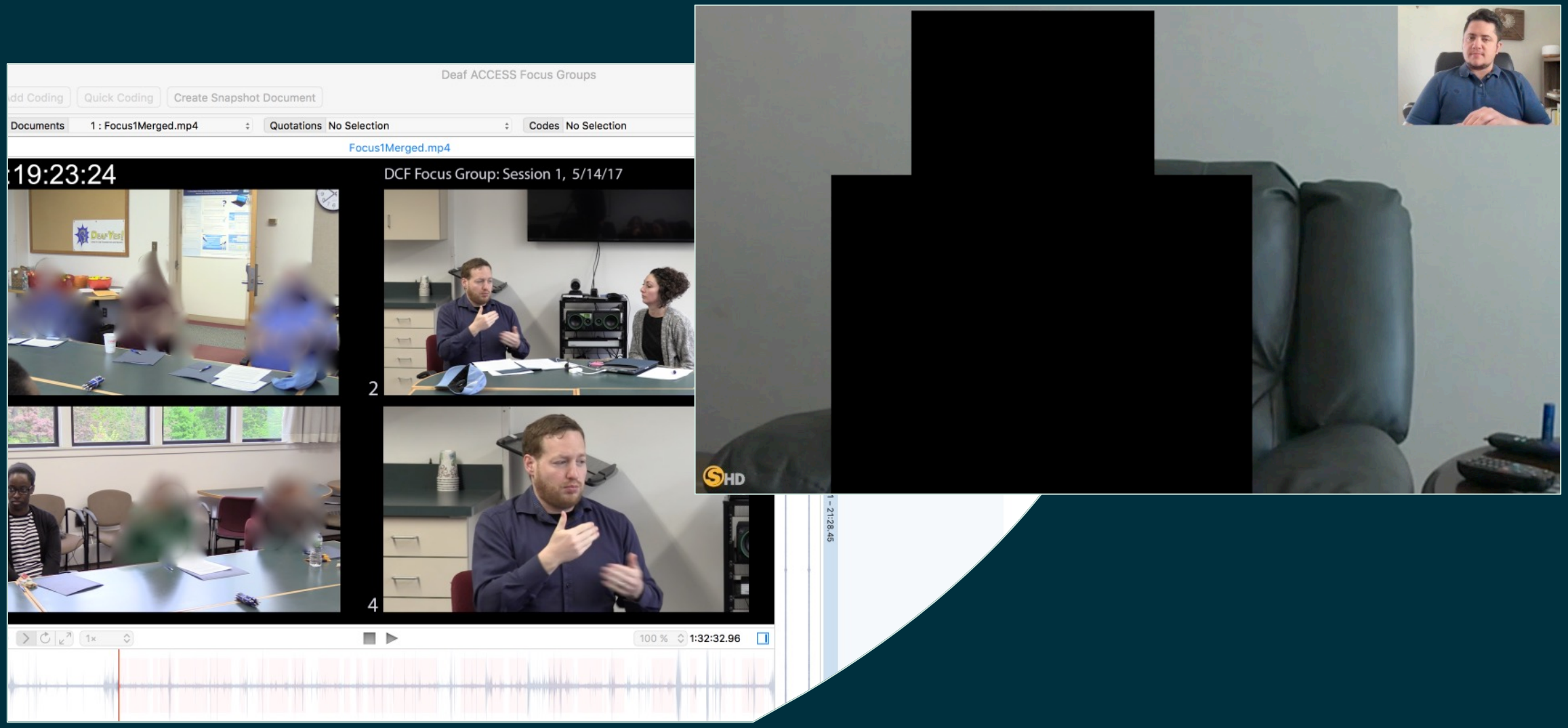
- Deaf leaders and co-leaders
- Deaf Community Advisors
- Hearing team members
  - “Right attitude”
- Intersectionality
- Collaboration as a guiding value



Research Questions

- Deaf person as a “whole human” (i.e., not just a broken ear to be studied)
- Focus on improving access
  - ~~Deaf accommodate hearing~~
  - Hearing accommodate Deaf
- Community input/guidance

Focus Groups/Interviews



Community Forums

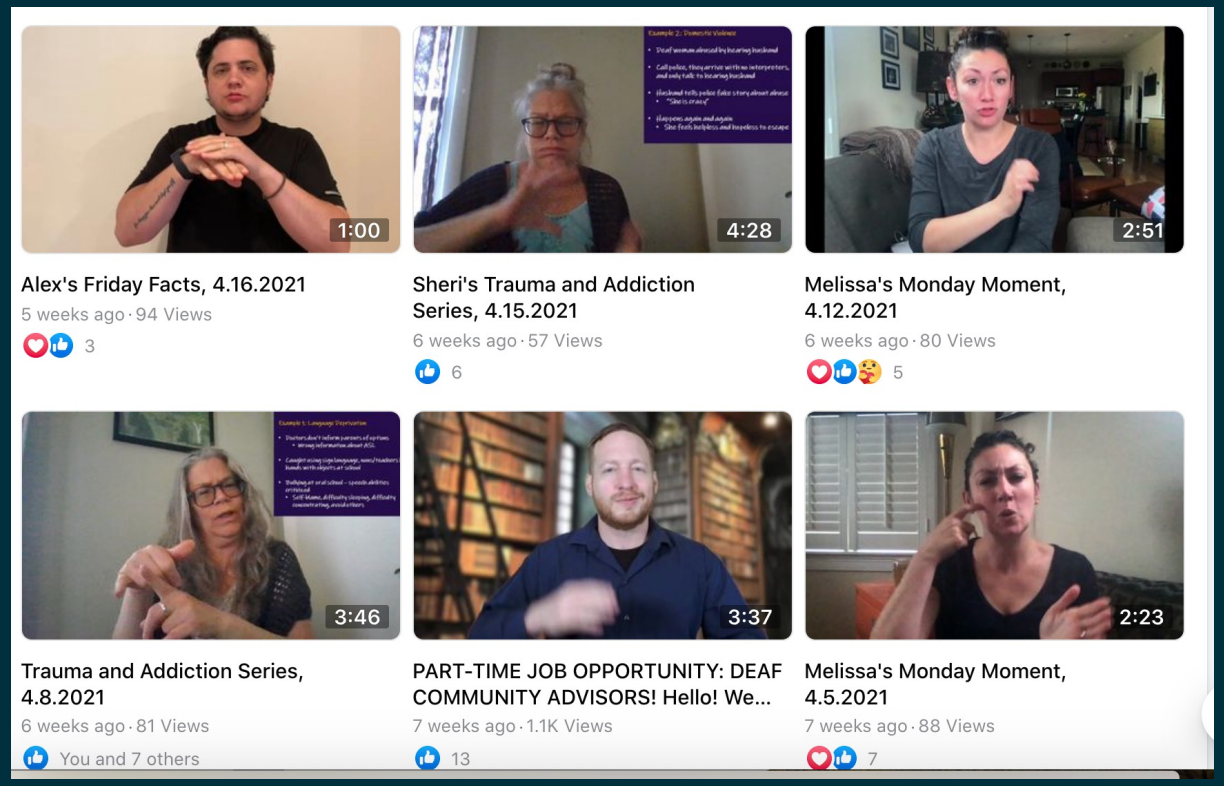
- Fall 2016
- “Deaf Space”
- Guided by the *Truth & Reconciliation Model*:
  - Open conversations about history of mistreatment
  - Institutional apology
  - Collaboratively exploring steps to move forward

Community Forums

- Themes:
  - General mistrust of hearing people
  - “Research in the general public is not for me”
  - Failure of researchers to communicate study results back to the Deaf community
  - Tendency of researchers to benefit from data provided by Deaf participants, with no efforts to “give back”

Transparency

- Dissemination via social media
- Increased visibility
- Emphasis on why research is important and how it will benefit the community

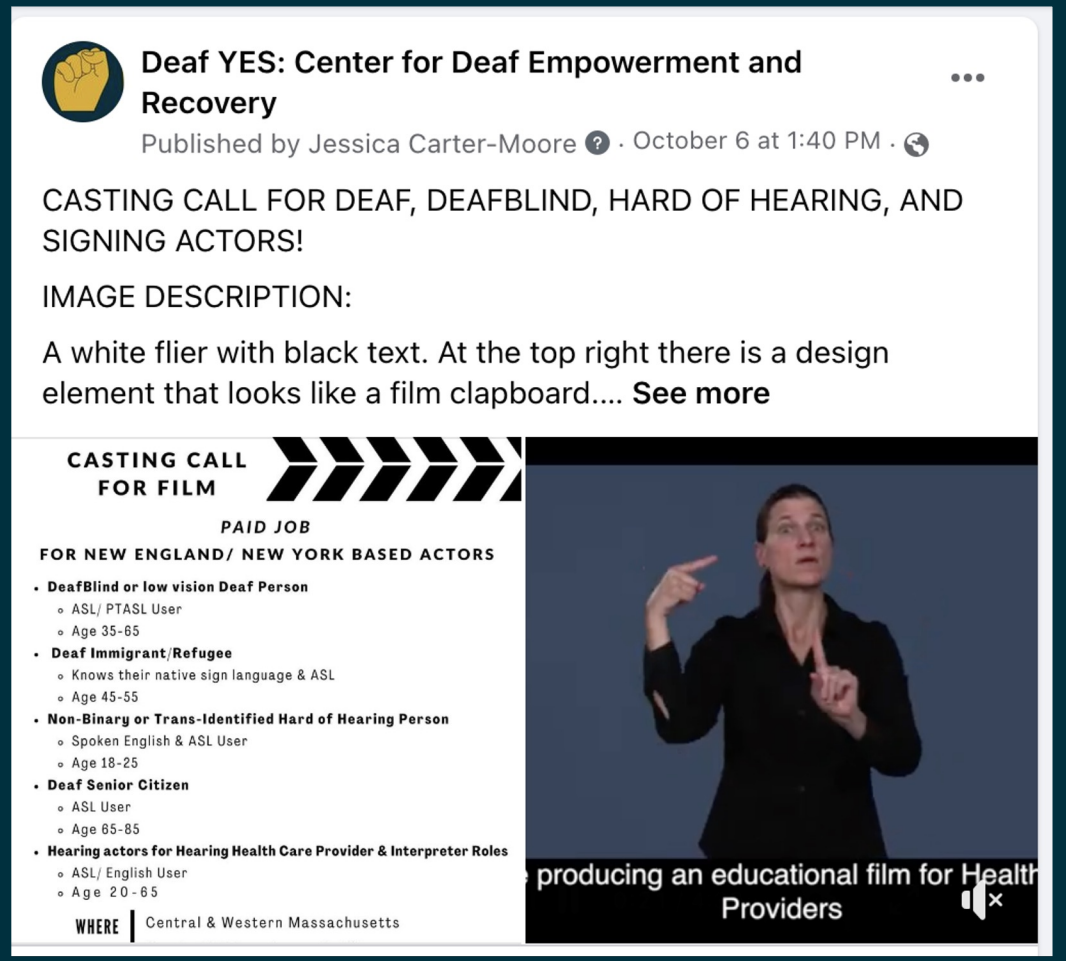


Community Outreach

- “Giving back”
  - Hiring community members
  - Paying participants fairly
  - Offering free presentations
  - Hosting community events
  - Therapy referral network
  - Creating open access interventions

Intervention Development

- Deaf directors
- ASL-fluent filmmaker
- Script writing process
- Casting call and auditions
- Script translation process
- Filmmaking process



Example 1 – Signs of Safety

Client-level therapy toolkit

Example 2 – QPR

Community-level training intervention

QPR: Part 3

Example 3 – Vital Signs

Provider-level training intervention

VITAL SIGNS

Panel Discussion

Why is community engagement in Deaf health research important?

Panel Discussion

What has been your experience with community-engaged research?

Panel Discussion

What are the unique considerations for Deaf community engagement work, as compared to the general population?

Panel Discussion

What are the challenges and benefits of conducting Deaf community-engaged research remotely?

Panel Discussion

What tips do you have for preparing for or starting a new collaboration with a Deaf organization?

Want to Learn More?

- Anderson ML, Riker T, Wilkins AM. Application of the truth and reconciliation model to meaningfully engage deaf sign language users in the research process. Cultur Divers Ethnic Minor Psychol. 2021 Jul 1:10.1037/cdp0000445. doi: 10.1037/cdp0000445. Epub ahead of print. PMID: 34197145; PMCID: PMC8720115.
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Update

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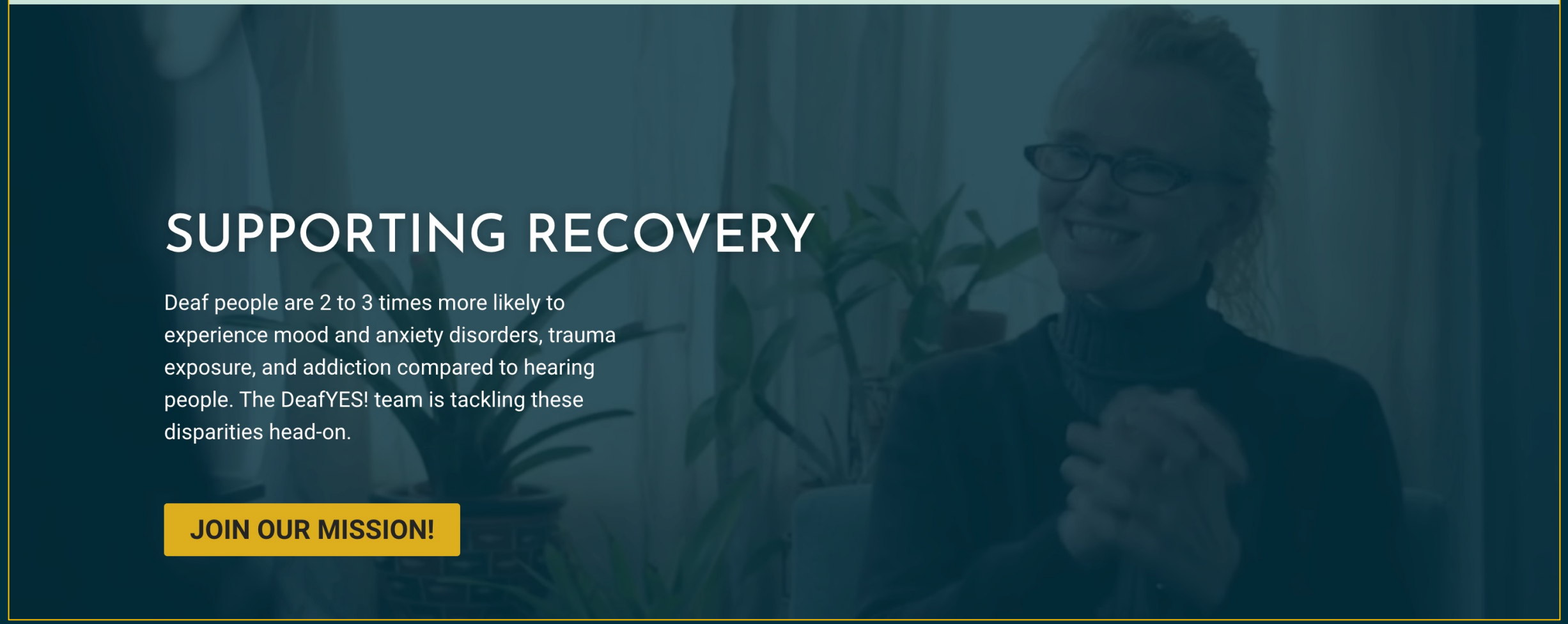
Center for Deaf Empowerment and Recovery

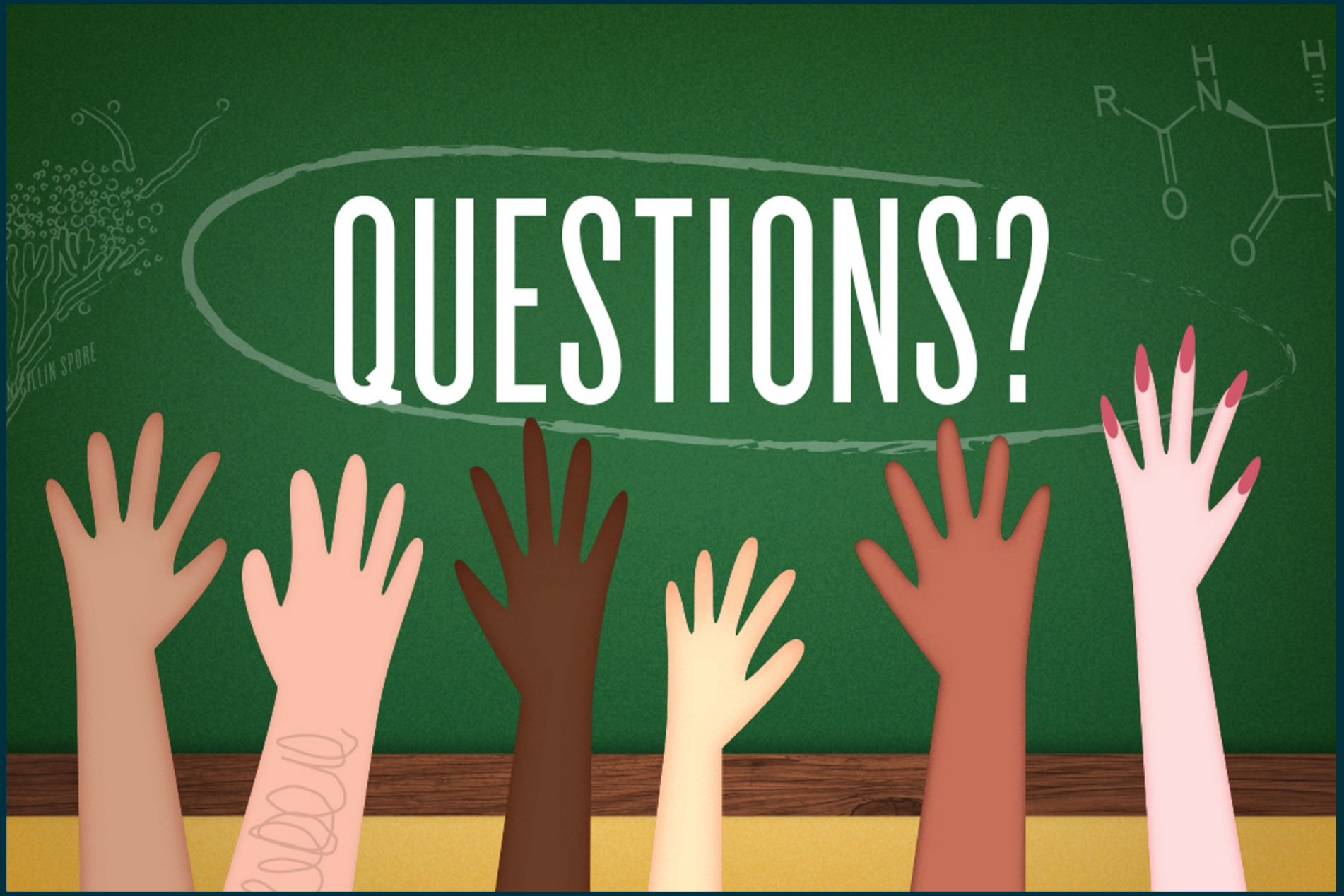
Who We Are | Our Research | Our Training | Our Services | Contact Us



SUPPORTING RECOVERY

Deaf people are 2 to 3 times more likely to experience mood and anxiety disorders, trauma exposure, and addiction compared to hearing people. The DeafYES! team is tackling these disparities head-on.

JOIN OUR MISSION!


QUESTIONS?