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

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

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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
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
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**?
What tips do you have for preparing for or starting a new collaboration with a Deaf organization?
Want to Learn More?


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!