

Disentangling Stigma: Applying Lessons from HIV to Hearing Care

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HLAA



Roadmap for this talk: Setting the stage for this panel

- Why focus on stigma?
- Definitions
- Moving to action to reduce stigma: Lessons from HIV
 - Key Principles for stigma reduction
 - Training Tools
 - The Total Facility Approach (TFA)

Why Focus on Stigma?

- Fundamental Determinant of Health and Health Equity
- Undermines three key determinants of health:
 - Access to resources
 - Access to social support
 - Psychological and behavioral responses

(Hatzenbuehler ML, Phelan JC, Link BG. Stigma as a fundamental cause of population health inequalities. Am J Public Health. 2013 May;103(5):813-21)



If we do not appreciate the nature and
impact of stigma, none of our
interventions can begin to be successful.

-Edward Cameron, Constitutional Court Justice, South Africa

Definitions and Types of Stigma

A word cloud of terms related to stigma, including Symbolic, Anticipated, Internalized, Intentions, Public, Self-perceived, Witnessed, Discrimination, Layered, Attributed, Courtesy, Associated, Heard, Experiencing, Enacted, Felt, Instrumental, Observed, Avoidant, Received, Normative, Self, Perceived, behavioral, and Secondary.

Stigma: A Social Process that Occurs within the Context of Power

1. Distinguishing and Labeling Differences

(Old person, person who uses substances, person with hearing difficulties)

2. Associating Negative Attributes

(stupid, incapable, frail, slow, burden, old, lazy)

3. Separating “Us” from “Them”

(physical and social isolation)

4. Status Loss and Discrimination

(denial of health care, verbal & physical abuse, loss of respect)

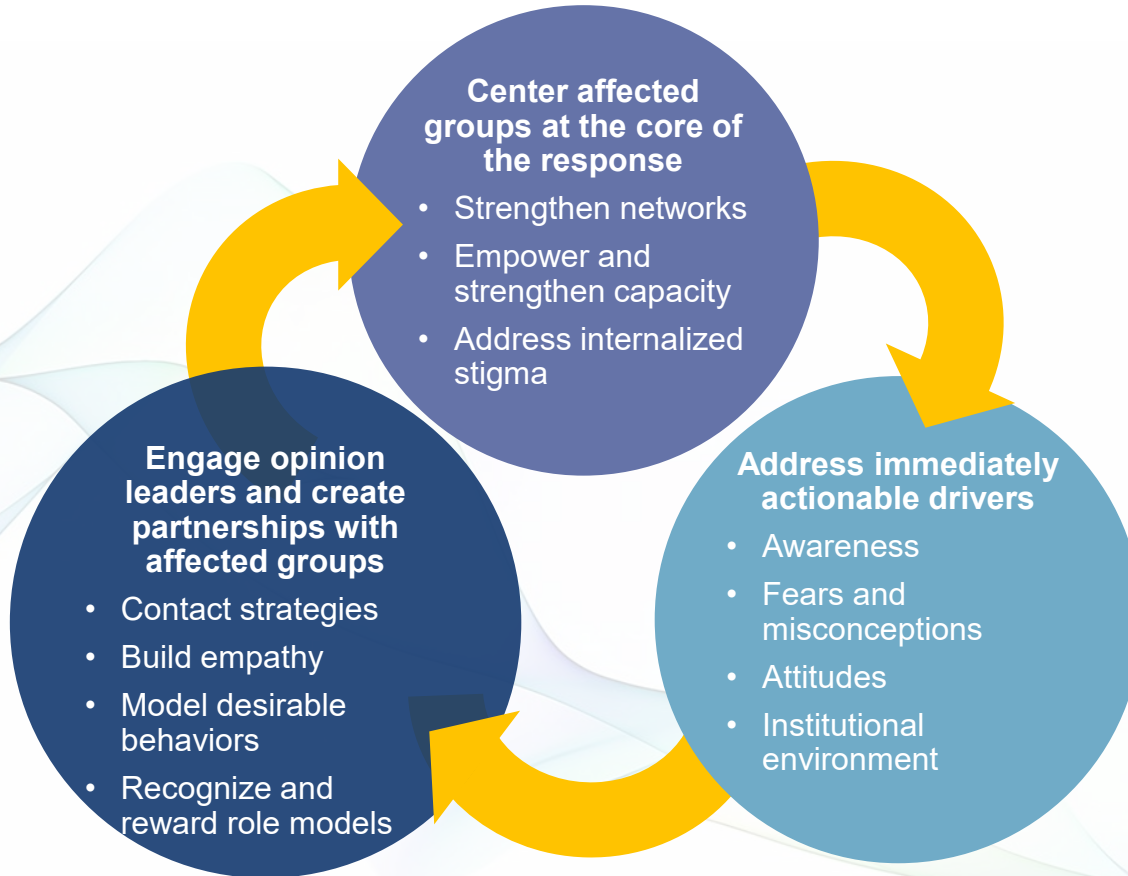
Types of Stigma

Experienced	Stigma that is enacted through interpersonal acts of discrimination <i>How often are you (shown less respect than others, excluded from activities) because you are...?</i> <i>Have you ever been denied a job (for example, someone refused to hire you), fired/sacked from a job or lost a job opportunity because you are ...?</i>
Perceived	Perception of the prevalence of stigmatizing attitudes in the community or among other groups (e.g., health care providers) <i>People think you are unfriendly or rude because you are...</i>
Anticipated	Fear of stigma, whether or not it is actually experienced <i>You worry people will think that you are older than you are when you wear your hearing device</i>
Internalized	Acceptance of experienced or perceived stigma as valid, justified <i>You feel embarrassed or ashamed because you are ...</i>
Secondary (Affiliate)	Stigma by association, extended to family or other caregivers of stigmatized individual <i>How often are you excluded from activities because your spouse is hard of hearing?</i>
Observed	Stigma happening to others that is witnessed or heard about <i>Patients or clients who are experiencing hearing loss/deafness have expressed to me the following concerns:</i> <i>People <u>think they are old</u> because of their hearing loss.</i> <i>People <u>pity or feel sorry for them</u> because of their hearing loss.</i>
Intersectional	When multiple social and structural factors that generate stigma intersect and create intersecting stigmas for individuals who are part of multiple marginalized groups



Taking Action: Key Principles for HIV Stigma Reduction Interventions

Three Key Principles for Reducing HIV Stigma



Stigma in Hearing Health



Why Focus on Stigma in Hearing Health Care?

- Importance of stigma as part of the lived experience of persons with hearing difficulties
- Stigma as a barrier across the hearing care pathway
 - Whether a person
 - Perceives a need for care
 - Desires care
 - Actively searches for services
 - Has Access to appropriate and thorough health assessments
 - Is included in health care decision making
 - Experiences inappropriate assumptions about their cognitive status
- Undermines optimal hearing health care outcomes
- Intertwining of stigma towards people with hearing difficulties and ageism



Stigma sub working group members

- Howard Francis (Co-Chair)
- *Laura Nyblade (Co-Chair)**
- *Jessica West**
- *Meg Wallhagen**
- *Rachel Stelmach**
- *Melissa Stockton**
- George Tavartkiladze
- Bolajoko Olusanya
- Catherine McMahon
- *John Kraemer**
- Suneela Garg

○ * Also members of the Research Implementing team

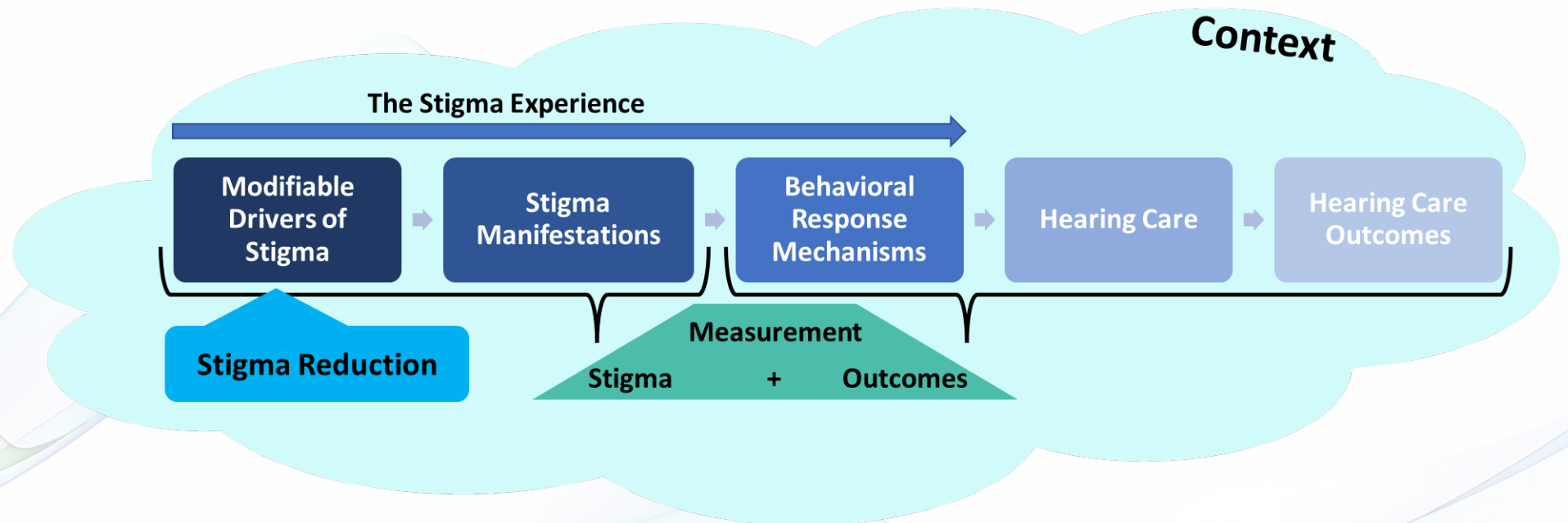
Research implementing team

- Neal Boafo
- Nana Akua Owusu
- Emma Gyamera
- Marco Nyarko
- Richard Vormawor
- Philip Gordon
- Khalida Saalim
- Elizabeth Troutman Adams
- Adam Preston
- Poorna Kushalnagar
- Lawrence Musa
- Ai Minakawa

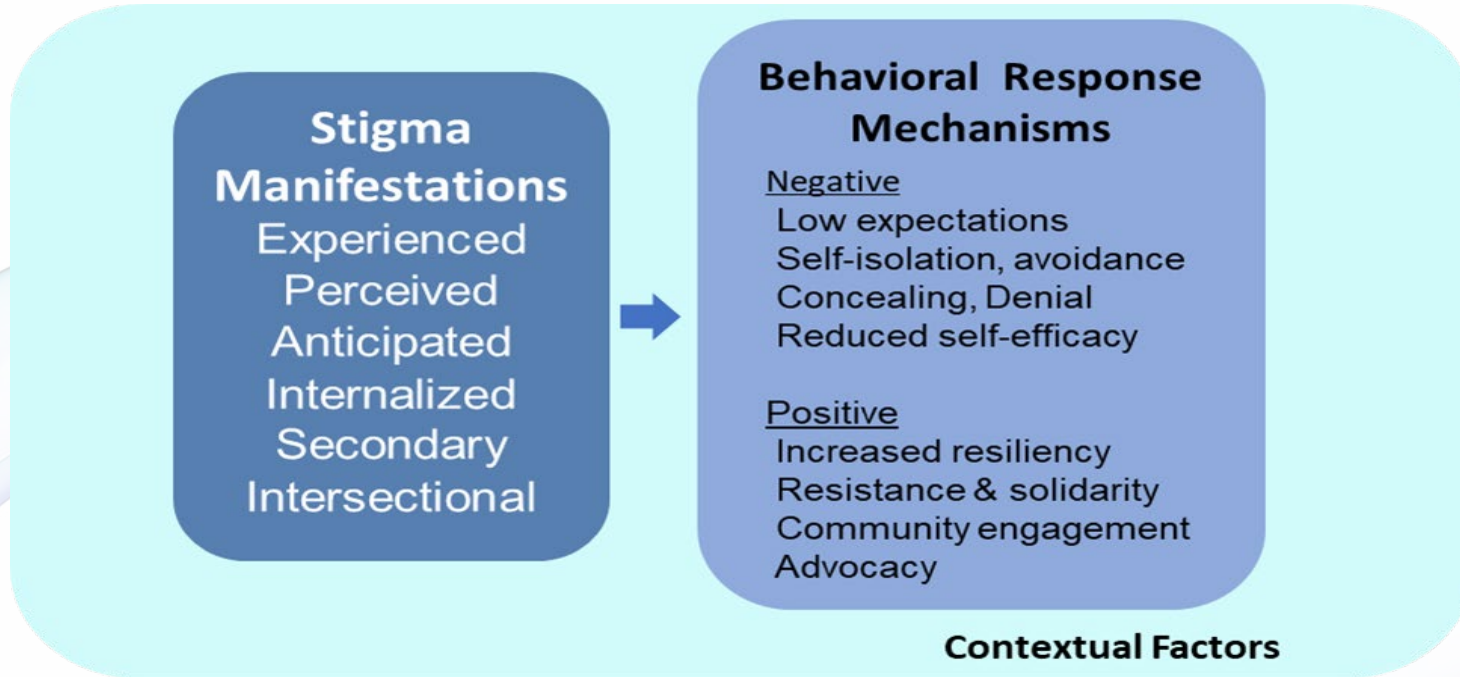
The LCHL stigma sub-group

- Developed a guiding, 'living' framework for action on stigma in hearing care
- Designed and preliminarily validated d/Deaf and Hard of Hearing stigma measures for use among a range of populations, that aligns with the framework
- ...Tested in the following locations
 - US (representing a High-Income Country) [All groups]
 - Ghana (representing a Low-Middle Income Country) [Lived experienced populations + parents]

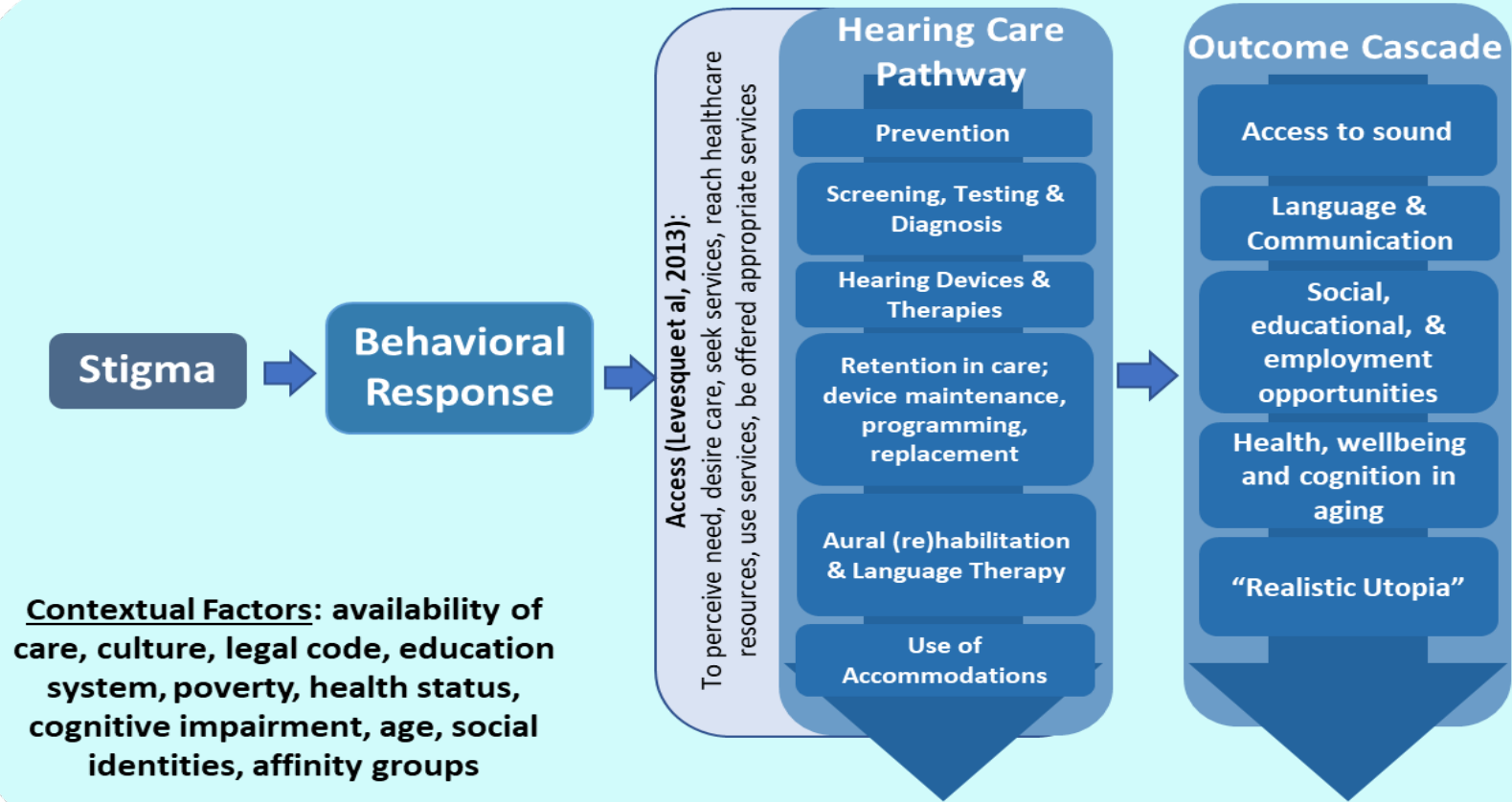
An Overview of Stigma and Hearing Health



The Stigma Experience's Impact



Stigma's Influence on Outcomes



Stigma Measurement: Necessary to Catalyze Action





Why Focus on Measurement?

- Measurement is critical to:
 - Understanding scale and dimensions of the challenge
 - Tracking change over time
 - Designing effective programs
 - Evaluating progress
 - Advocacy: required for policy change and funding

Five step measures development process



(1) Initial Survey Development

Literature review
Survey item abstraction
Draft questionnaire



(2) Modified Delphi Process

Internal technical subworking group review
External focus group discussions with experts and members of populations of interest



(3) Cognitive interviewing

Cognitive interview survey items
Refine



(4) Pre-testing

Pre-test survey items
Refine



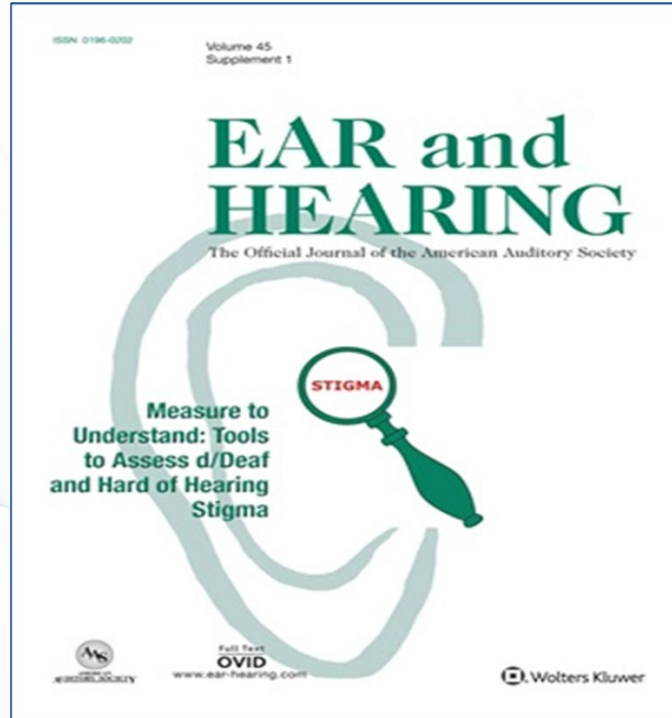
(5) Psychometric Validation

Validation Survey
Psychometric analysis

Broad Summary of Developed & Tested Stigma Measures

Type of stigma	Population				
	Lived experience	Parents	Care partners	Health care providers	General Population
Experienced	X			X (Secondhand)	
Enacted				X	
Perceived	X	X	X	X (Own & Secondhand)	
Internalized	X				
Secondary (perceived, experienced & Internalized)		X	X		
Observed		X	X		
Hearing device	X	X	X	X	
Ageism	X		X	X	X

Measures are published in a special supplement to Ear and Hearing



Acknowledgments

The background of the slide features a series of overlapping, translucent, wavy lines that flow from the left side towards the right. These lines are colored in a gradient of light blue, teal, and pale purple, creating a sense of movement and depth. The top half of the slide is a solid light blue, and the bottom half is a solid white, with the wavy lines crossing the boundary between them. A dark blue horizontal bar is visible at the very bottom of the image.

Acknowledgments

- The Lancet Commission on Hearing Loss
- The sub-committee on stigma
- The research team
- All the study participants
- This work would not have been possible without financial support from RTI, International and The Lancet Commission on Hearing Loss