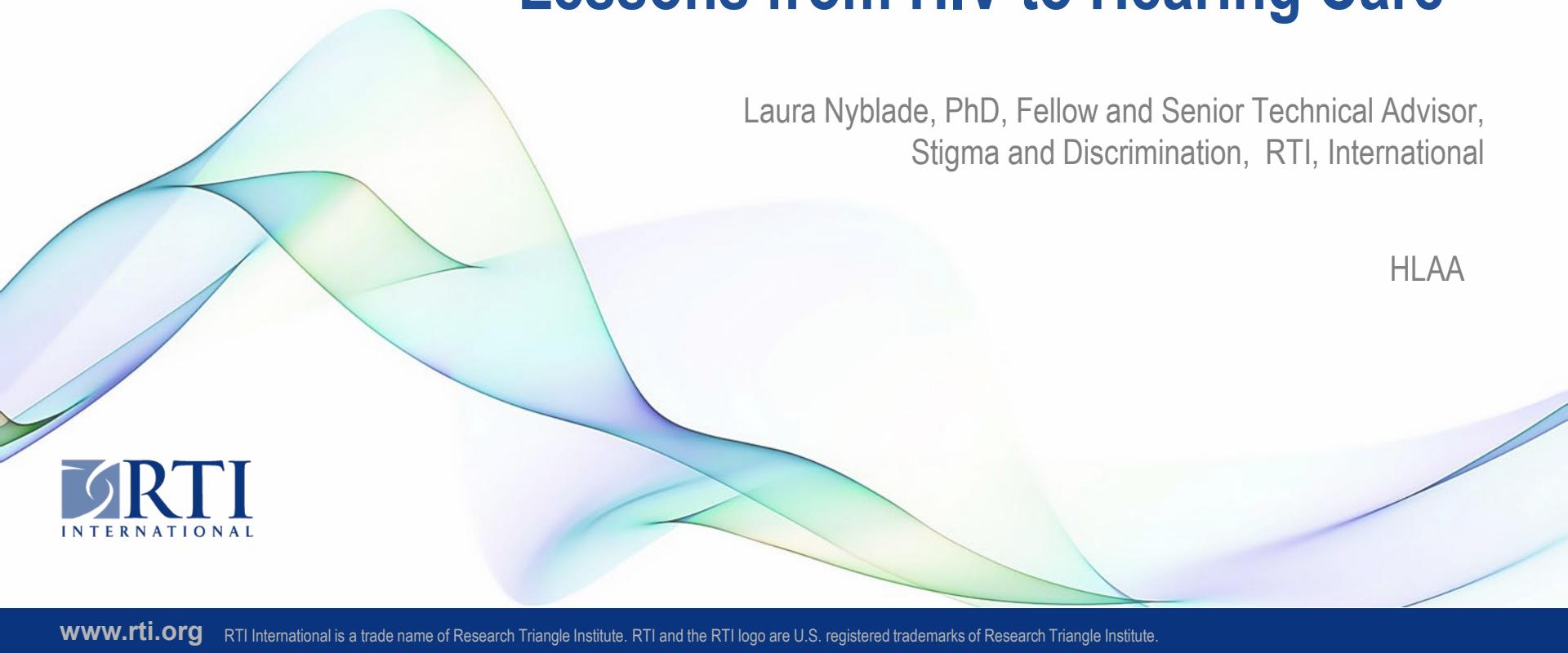


# Disentangling Stigma: Applying Lessons from HIV to Hearing Care



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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

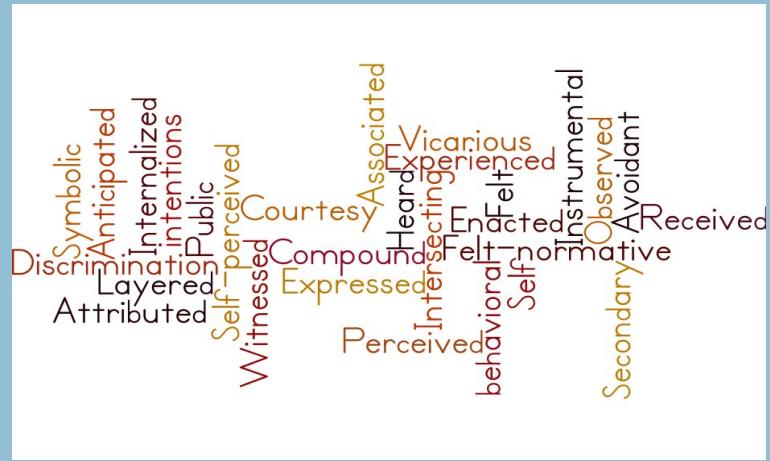
(Hatzenbuehler ML, Phelan JC, Link BG. Stigma as a fundamental cause of population health inequalities. Am J Public Health. 2013 May;103(5):813-21)



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



# 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

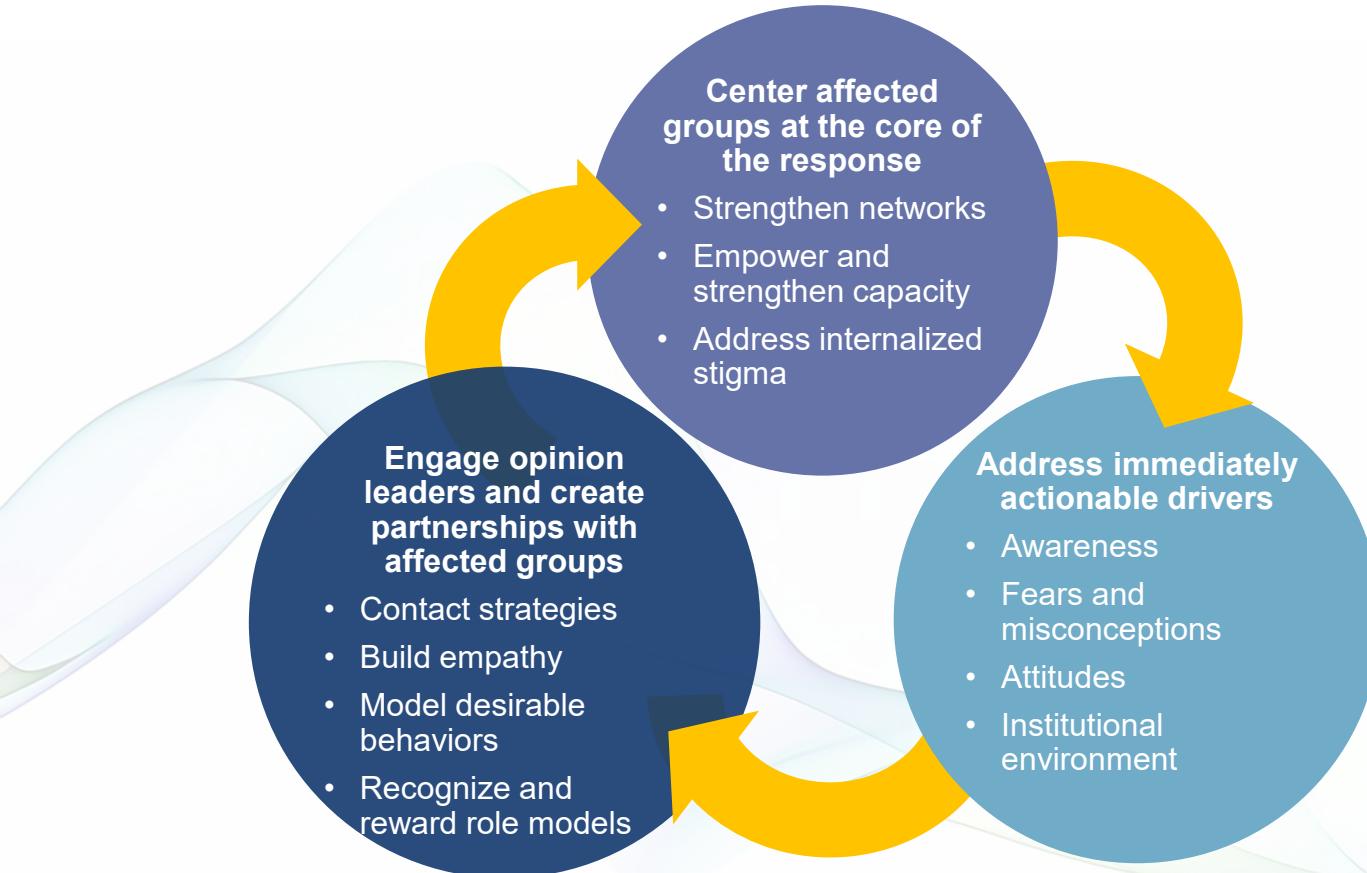
(denial of health care, verbal & physical abuse, loss of respect)

# Types of Stigma

Experienced	<b>Stigma that is enacted through interpersonal acts of discrimination</b> <i>How often are you (shown less respect than others, excluded from activities) because you are...? 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	<b>Perception of the prevalence of stigmatizing attitudes in the community or among other groups (e.g., health care providers)</b> <i>People think you are unfriendly or rude because you are...</i>
Anticipated	<b>Fear of stigma, whether or not it is actually experienced</b> <i>You worry people will think that you are older than you are when you wear your hearing device</i>
Internalized	<b>Acceptance of experienced or perceived stigma as valid, justified</b> <i>You feel embarrassed or ashamed because you are ...</i>
Secondary (Affiliate)	<b>Stigma by association, extended to family or other caregivers of stigmatized individual</b> <i>How often are you excluded from activities because your spouse is hard of hearing?</i>
Observed	<b>Stigma happening to others that is witnessed or heard about</b> <i>Patients or clients who are experiencing hearing loss/deafness have expressed to me the following concerns: People <u>think they are old</u> because of their hearing loss. People <u>pity</u> or <u>feel sorry</u> for them 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**

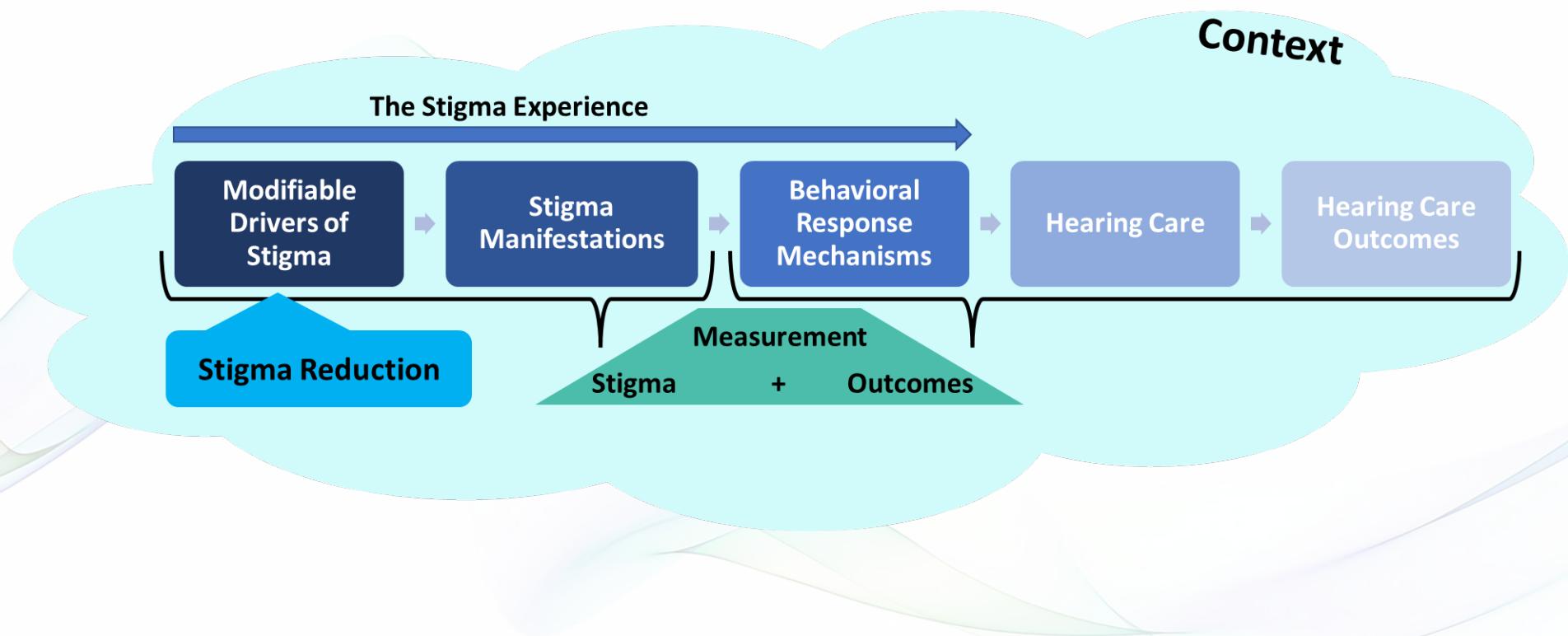
## Research implementing team

- 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

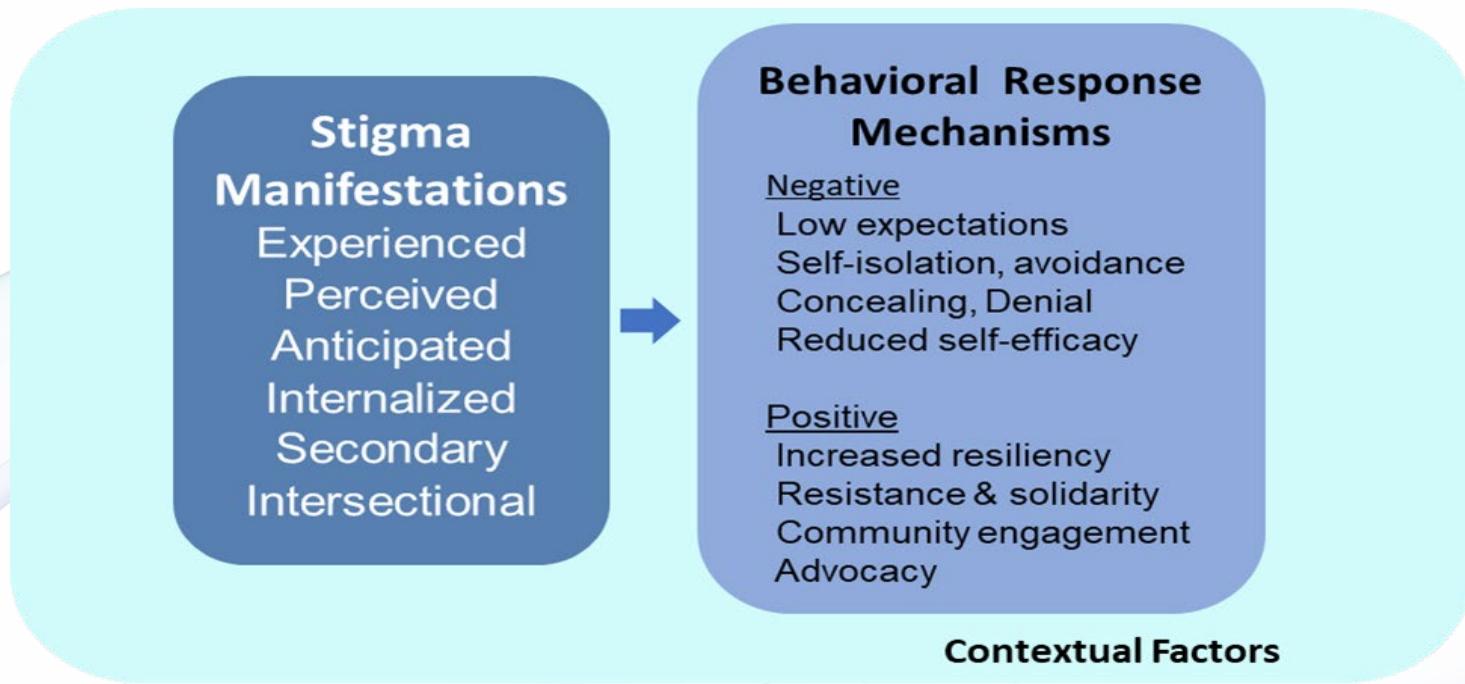
# The LCHL stigma sub-group

- 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



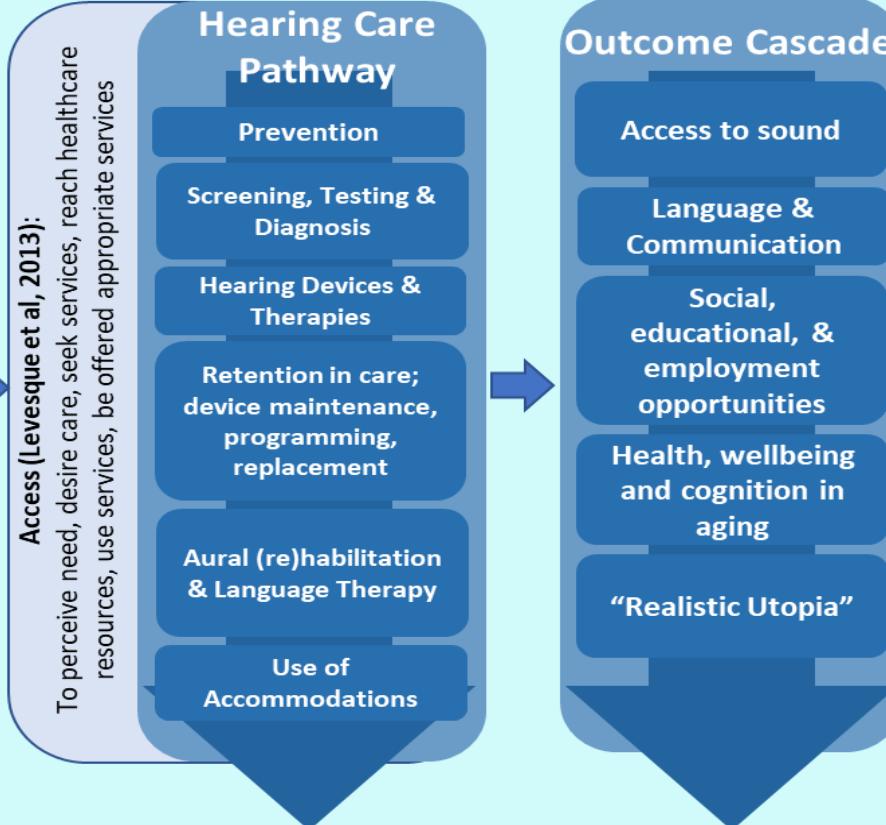
# The Stigma Experience's Impact



# Stigma's Influence on Outcomes

Stigma → Behavioral Response

Contextual Factors: availability of care, culture, legal code, education system, poverty, health status, cognitive impairment, age, social identities, affinity groups



# 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

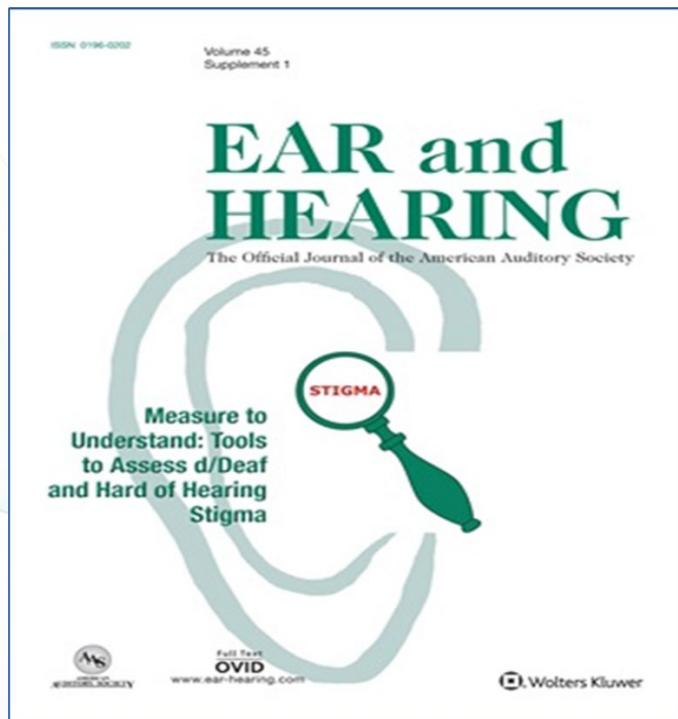
Validation Survey

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

# Acknowledgments

- The Lancet Commission on Hearing Loss
- The sub-committee on stigma
- The research team
- All the study participants
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