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Development of Measures for d/Deaf and Hard of Hearing Stigma: Introduction to the Special Issue on Stigma Measurement

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Abstract

People who are d/Deaf or hard of hearing (d/DHH) often experience stigma and discrimination in their daily lives. Qualitative research describing their lived experiences has provided useful, in-depth insights into the pervasiveness of stigma. Quantitative measures could facilitate further investigation of the scope of this phenomenon. Thus, under the auspices of the *Lancet* Commission on Hearing Loss (LCHL), we developed and preliminarily validated survey measures of different types of stigma related to d/Deafness and hearing loss in the United States (a high-income country) and Ghana (a lower-middle income country). In this introductory paper, we first present working definitions of the different types of stigma; an overview of what is known about stigma in the context of hearing loss; and the motivation underlying the development of measures that capture different types of stigma from the perspectives of different key groups. We then describe the mixed-methods exploratory sequential approach used to develop the stigma measures for several key groups: people who are d/DHH, parents of children who are d/DHH, care partners of people who are d/DHH, healthcare providers, and the general population. The subsequent manuscripts in this supplemental issue of *Ear and Hearing* describe the psychometric validation of the various stigma scales developed using these methods.

INTRODUCTION

This special issue is a product of the *Lancet* Commission on Hearing Loss (LCHL), a multinational effort to map a new approach to reducing the global burden of disability associated with hearing loss (Wilson et al. 2019). During early meetings of the LCHL, commissioners identified stigma as a cross-cutting issue that may affect the LCHL initiatives designed to mitigate the negative effect of hearing loss in both high-income and low- and middle-income (LMIC) settings. As such, the LCHL Measures, Models and Stigma Reduction Subgroup (henceforth, the stigma subgroup) was convened; all members are co-authors of this manuscript. The purpose of the stigma subgroup was to advance our understanding of hearing loss stigma and actions to address it. Learning from stigma research across multiple stigmatized health conditions, the stigma subgroup identified the lack of a comprehensive set of measures to capture the different types of stigma faced by diverse groups of d/Deaf and hard of hearing (d/DHH) populations. After much consultation with the stigma subgroup and review of current literature, we chose to use the term d/DHH here to encompass this diverse group, given the term has been used to

inclusively describe deaf individuals who are culturally Deaf, deaf individuals who do not identify with the Deaf community, as well as others with a range hearing difficulties (Linton 1998; Brueggemann 2009; McIlroy & Storbeck 2011; Canadian Association of the Deaf 2015; National Association of the Deaf 2024). Measures would allow future research to characterize the nature and magnitude of stigma; understand the relations between different types of stigma, health, and other life outcomes; and design and evaluate targeted stigma-reduction interventions. Thus, we developed and preliminarily validated survey measures of different types of stigma related to deafness and hearing loss in the United States (U.S., a high-income country) and Ghana (a LMIC), the results of which are presented in this supplemental issue of *Ear and Hearing*.

There are two main sections of this introductory paper. In the first section, we present working definitions of the different types of stigma, provide an overview of what is known about stigma in the context of hearing loss, and explain the motivation underlying the development of measures that capture different types of stigma from the perspective of different stakeholders. In the second section, we describe the exploratory, mixed-methods sequential process used for developing several stigma measures for people who are d/DHH, parents of children who are d/DHH, care partners of adults who are d/DHH, healthcare providers, and the general population. The preliminary psychometric validation results of these measures are not described in this introductory manuscript but rather are presented in the subsequent manuscripts in this supplemental issue. These include measures related to populations who are d/DHH (Stelmach et al. this issue pp. XXXX), care partners of adults who are d/DHH (Wallhagen et al. this issue pp. XXXX), parents of children who are d/DHH (Saalim et al. this issue pp. XXXX), HCPs (Troutman Adams et al. this issue pp. XXXX), stigma related to hearing devices (West et al. this issue pp. XXXX) and ageism (Nyblade et al. this issue pp. XXXX).

STIGMA IN THE CONTEXT OF HEARING LOSS

Stigma defined

Stigma is a relational phenomenon that occurs when one possesses, or is thought to possess, certain attributes that suggest a condition or social identity that others consider to be of little value, abnormal, or undesirable in a particular social context (Goffman 1963; Becker 1981; Crocker et al. 1998). The social process of stigmatization occurs within the context of power and follows a series of steps: a) identifying and labeling differences; b) linking negative or undesirable characteristics to those differences; c) separating or distancing from individuals with those characteristics, creating a distinction between “us” and “them;” and d) inflicting status loss and discrimination on stigmatized individuals (Link & Phelan 2001). Discrimination is the unfair and unjust action toward an individual or group on the basis of real or perceived status or attributes, for example a health condition, socioeconomic status, gender, race, or age (UNAIDS 2000). Intersectional stigma occurs when multiple social and structural factors that generate stigma converge and amplify negative effects of stigma associated with membership in multiple marginalized groups (Turan et al. 2019; Sievwright et al. 2022).

Stigma comes in various types and manifests in multiple ways (Nyblade et al. 2021), as defined in Table 1. *Experienced stigma* happens when people enact stigma on each other, often unconsciously, through interpersonal acts of discrimination. *Perceived stigma* is one's perception or understanding of how prevalent stigma is and how stigmatized individuals or groups are treated. *Internalized stigma* (also known as self or affiliative stigma) is when individuals accept and internalize external stigma as true and valid. *Anticipated stigma* is the fear or expectation that stigma will happen. *Observed stigma* (or witnessed stigma) refers to hearing stories about or witnessing interpersonal discrimination towards others. In addition to direct effects on the stigmatized individual, stigma may also spill over to effect people close to or in proximity to stigmatized individuals. *Secondary stigma*, sometimes also called associative or courtesy stigma, is experienced by individuals associated with a stigmatized person. This concept has also been described as third-party disability, or the experience of disability among close contacts due to the experience of a significant other, such as a friend, family member, or partner (World Health Organization 2001).

While complex, measuring the different types and manifestations of stigma is feasible with distinct tools for various key groups. Briefly, different types of questions are required to capture different types of stigma. For example, while measuring *experienced* stigma requires questions that ask about one's actual experiences of interpersonal acts of discrimination, measuring *perceived* stigma requires questions that ask about one's perception of commonly held stigmatizing beliefs. Further, accurately measuring any one type of stigma requires understanding how that stigma manifests. For example, measuring experienced stigma first requires an understanding of what interpersonal acts of discrimination look like (e.g. verbal abuse, exclusion), where they take place (e.g. school, workplace), and who enacts them (e.g. family, employers). Similarly, measuring perceived stigma requires an understanding of the commonly held negative stereotypes or beliefs attributed to the health condition or group. We know from studying other widely stigmatized conditions – such as human immunodeficiency virus (HIV) and mental illness – that it is important to measure different types of stigma from the perspectives of the different individuals involved in the stigmatization process, including: the stigmatized individuals themselves; individuals close to them (e.g. parents, care partners); individuals involved in healthcare; and members of their community (e.g. the general population) (van Brakel et al. 2019). Finally, all of these different types and manifestations of stigma may vary across the life course and differing cultural contexts, which might necessitate specific measurement tools by group. However, stigma manifestations and consequences can also be remarkably similar across contexts (van Brakel et al. 2019); allowing different populations to respond to the same set of questions will facilitate comparisons across different settings and populations.

Stigma faced by people who are d/DHH

More than 1.5 billion people – about 23% of the world's population – experience hearing impairment (World Health Organization 2021) and therefore may face stigma. A growing body of literature on stigma and discrimination in the context of hearing loss and impairment documents that populations of people who are d/DHH and those close to them—such as parents, care partners, or even healthcare providers —experience, observe or perpetuate stigma and discrimination in many aspects of their daily lives, including in

family, community, education, workplace, and healthcare settings (David & Werner 2016; Wallhagen 2018; Ruusuvuori et al. 2021). Negative stereotypes and stigmatizing beliefs associated with being d/DHH or using a hearing device persist across the globe. Depending on cultural context and beliefs, d/Deafness may be associated with misfortune due to natural causes, such as heredity, noise, or poor aural hygiene, and unnatural causes such as sorcery or retribution (Stephens et al. 2000; Olusanya 2015; World Health Organization 2021). In addition, individuals who are d/DHH may be perceived as unfriendly, less confident, disabled, or weak (Franks & Beckmann 1985; Doggett et al. 1998; Kochkin 2007). Although many older adults experience hearing loss as they age, hearing loss earlier in life may be mischaracterized as due to aging (Oyer & Oyer 1985; Hétu 1996; Erler & Garstecki 2002). Moreover, hearing loss and/or the use of visible hearing devices may be deemed unattractive, associated with a lack of intelligence, or considered a sign of aging (Blood et al. 1977; Becker 1981; Johnson et al. 2005; Wallhagen 2010), although negative perceptions of hearing aid use and aging are not universal (Ryan et al. 2007).

Reflecting the diversity of the lived experience of people who are d/DHH, individual vulnerability to stigma and the nature and effect of stigma may vary by social identity, peer support, primary means of communication, language modality in the home, hearing device usage, and stage of the life course (Davis et al. 2016; Russ et al. 2018). Although the hearing world often portrays hearing loss and d/Deafness as a negative condition, culturally Deaf individuals view their deafness with pride because it indicates common and shared history, social customs, language, and identity (Middleton et al. 1998; Padden & Humphries 2006). As such, the experience with stigma among Deaf individuals is likely to differ from other groups of individuals who are d/DHH. Further, those who rely on visual communication (e.g., sign language) may experience marginalization if these forms of communication highlight their “otherness” from hearing peers (Coryell et al. 1992; Mousley & Chaudoir 2018). In particular, children who are d/DHH in homes where language is primarily spoken and schools that lack accommodations to make spoken language accessible may be perpetually isolated from their non-signing peers and family members (Hauser et al. 2010; Batten et al. 2014).

In the early stages of the life course, stigma may exacerbate the risk that young children who are d/DHH face language delay and social and educational underachievement in the absence of access to spoken language or sign language (Kennedy et al. 2006). The role of the parents and other care providers in facilitating communication and development of language for children who are d/DHH is critical; however, children’s experiences with stigma, including shame and fear, may have implications for diagnosis acceptance, care seeking, development of language, social and emotional skills, and access to rehabilitation services (Kennedy et al. 2006; Ebrahimi et al. 2015; Ravi et al. 2016; Chang 2017). As parental concerns change over time and along the intervention pathway, stigma may also play a role in parental decision-making around their children’s language, communication, technology use, health, and education (Burger et al. 2005). In later childhood, stigma may effect mental, emotional, and social health and development, hearing device use, and the educational experience of youth who are d/DHH (Dreyzehner & Goldberg 2019).

As individuals who are d/DHH age into early adulthood, stigma may negatively effect their ability to attain traditionally conceptualized markers of adulthood, such as higher-level education, financial independence, full-time employment, marriage, or having children (Janus 2009; Shandra 2011; Mann & Honeycutt 2014). Furthermore, the experience of stigma as one ages increasingly involves decision-making and navigation of identity management in a variety of new settings (West et al. 2016), including the workplace, where individuals who are d/DHH may be fired or not hired at all at higher rates than their hearing peers (Komesaroff 2004; Jennings et al. 2013). In late adulthood, the adverse effects of increasing hearing disability include communication difficulties and isolation that are perpetuated, in some cultures, by stigma around hearing device usage or the fear that using a hearing device may increase exposure to ageism (or age discrimination) (Wallhagen 2010; McKee et al. 2015; Ruusuvuori et al. 2021). Further, the internalization of stigma and stereotypes associated with aging in this later life stage may impair hearing care outcomes, as well as physical, mental, and cognitive health (Levy 2009; Wallhagen 2010). For example, older individuals who hold more ageist stereotypes have been shown to have more incident hearing loss than those with more positive views of aging (Levy 2009).

Taken together, stigma in its many forms has been shown to negatively effect people who are d/DHH with potential implications for development, achievement, health, healthcare engagement, and well-being. Concerns among individuals who are d/DHH regarding how others will react to their hearing loss or deafness (Erdman & Demorest 1998; Kricos et al. 2007) may lead to delays in acknowledging their hearing loss (Kochkin 1990, 1993; Hétu 1996; Hallberg 1999; Noble 2009); seeking care for their hearing (Blood et al. 1977; Kochkin 2000, 2007; Southall et al. 2009); or, for those who have access, are eligible, and can afford them, making decisions about the use of hearing devices (Wallhagen 2010; Southall et al. 2010; Ruusuvuori et al. 2021). Stigma may factor into individuals' denial of hearing loss (Noble 2009; Dawes et al. 2014) and rejection of hearing devices (Meister et al. 2008; McKee et al. 2019; Ruusuvuori et al. 2021). In addition, because communication is central to identity formation, social interaction, and status, experiencing communication challenges may cause shame or fear of ostracization and discrimination, especially for underprivileged and marginalized groups (Bouton 2013). For older individuals who experience ageism, stigma may complicate their acceptance of age-related hearing loss, which often results in delayed intervention (Wallhagen 2010). As such, stigma can hamper both access to and engagement with quality hearing healthcare and undermine emotional, social, and economic well-being. While the evidence of stigma faced by people who are d/DHH and the negative effect of this stigma is growing, the field of hearing care largely lacks comprehensive tools specifically designed to measure the different types and manifestations of stigma.

The importance of measuring d/DHH stigma

The field of stigma research and intervention programming (Stangl et al. 2019; Nyblade et al. 2021), suggests measurement tools for the different types and manifestations of d/DHH stigma among diverse populations are needed. Foremost, developing measures will complement qualitative research methods and allow for quantifying the role of stigma in health and behavior. Developing measures is a necessary precursor to developing effective

stigma-reduction interventions that can be appropriately evaluated. As different types and manifestations of stigma may effect treatment seeking behaviors and outcomes differently, specific measures are needed to evaluate targeted interventions (Levesque et al. 2013). Given the great diversity of populations who are d/DHH across and within different stages of life, cultures, and contexts, the perceptions, experiences, and effects of stigma and its effect on hearing healthcare may equally vary (Cabral et al. 2013; Davis et al. 2016; Russ et al. 2018). Valid, comparable, and complementary measures are thus needed to describe the prevalence of stigma in these different groups, cultures, and contexts. For other stigmatized health conditions, stigma measures and interventions that work well across diverse settings and populations have been established, which suggests that the development of comparable stigma measures could facilitate global, cross-cultural research and intervention. (Ogden & Nyblade 2005; Pescosolido et al. 2013; Stangl et al. 2019; van Brakel et al. 2019).

Despite decades of research recognizing the existence of stigma for individuals who are d/DHH, there are some gaps in the literature. First, studies have only recently begun to quantify certain aspects of stigma among people who are d/DHH by, for example, including a stigma sub-scale in a quality-of-life measure, or by adapting internalized stigma items originally used for other widely stigmatized conditions such as mental illness or HIV (Patrick et al. 2011; Vincent et al. 2017; Mousley & Chaudoir 2018). In addition, stigma measures are lacking for individuals who are close to people who are d/DHH, such as parents of children and care partners of adults, both groups critical to the support and wellbeing of people who are d/DHH. There is also a lack of measures capturing stigmatizing attitudes and behaviors among those who may, often inadvertently, perpetuate stigma, such as the general population or even healthcare providers. Moreover, most research on populations that are d/DHH has occurred in high-income settings (Pascolini & Smith 2009; Stevens et al. 2013; West et al. 2021), while more than 80% of people who are d/DHH reside in LMICs (West et al. 2021; World Health Organization 2021). As such, there is still a need for the development of a set of comprehensive measures to capture the breadth of different types of d/DHH stigma among diverse populations with different lived experiences and in varying socioeconomic and cultural contexts.

DEVELOPING COMPREHENSIVE MEASURES OF d/DHH STIGMA

We aimed to develop and preliminarily validate measures in both a high-income country (U.S.) and a LMIC (Ghana) to quantify different types of d/DHH stigma across a) populations with direct lived experience of being d/DHH and b) parents of children who are d/DHH. In the U.S., the study also developed and validated measures with care partners (including spouses, partners, or others – such as an adult child or relative) of adult persons who are d/DHH, healthcare providers (HCPs), and the general population. Balancing the call for global measures that could be used cross-culturally and across income settings with the practical scope and limited timeframe of the project, these two countries were chosen as feasible study sites that represented both a high-income country and a LMIC. For the purposes of this manuscript and recruitment into the larger study, individuals who have been d/DHH since before language development are henceforth referred to as “lifelong” d/DHH. Individuals who became d/DHH in adulthood or after spoken language development are henceforth referred to as “acquired” d/DHH. The focus on these two groups – lifelong

d/DHH and acquired d/DHH – was an intentional decision to capture a wide breadth of lived experience, but is not explicitly derived from a clinical definition or age of onset.

The measures were developed using an exploratory sequential design, through a multi-step process including: (1) Initial Survey Development, (2) Modified Delphi Process, (3) Cognitive Interviewing, and (4) Pre-testing (Fetters et al. 2013). The fifth and final step in the process, (5) Psychometric Validation, for each measure is presented in the following manuscripts in this supplement of *Ear and Hearing:* populations who are d/DHH (Stelmach et al. this issue pp. XXXX), care partners of adults who are d/DHH (Wallhagen et al. this issue pp. XXXX), parents of children who are d/DHH (Saalim et al. this issue pp. XXXX), HCPs (Troutman Adams et al. this issue pp. XXXX), stigma related to hearing devices (West et al. this issue pp. XXXX) and ageism (Nyblade et al. this issue pp. XXXX). For the validation activities (steps 3–5), we obtained ethics approvals from the institutional review boards (IRBs) at RTI International, the Ghana Health Services Ethics Committee, and the Korle Bu Teaching Hospital. All participants provided written informed consent. The five stages of this process are detailed in Figure 1, which also serves as a joint display. (Fetters et al. 2013). Our joint display documents how we used qualitative methods to build survey measures, as described in the following subsections of this manuscript, which ultimately are psychometrically and quantitively evaluated in the subsequent manuscripts in this supplemental issue.

Step 1: Initial Survey Development

To develop an initial set of items, we conducted a scoping literature review to identify studies (n = 34) that included survey questions or quantitative measures for any aspect of d/DHH stigma (See text document, Supplemental Digital Content 1, which contains the search terms and engine). One co-author (MS) reviewed the abstracts of articles to identify studies that used quantified stigma in the context of hearing loss broadly. While there was no restriction on study type, the article had to include a quantitative measure. Following the abstract review, two co-authors (MS & JW) conducted a full-text review and abstracted the survey items of the identified measures. The reference lists of included articles were mined for additional relevant sources. Identified literature included survey measures capturing the attitudes toward different types of hearing loss at different life stages; toward the use of hearing devices such as hearing aids; and about the stigma experienced, anticipated, perceived, and internalized among individuals with different types of hearing loss and their care partners, as well as ageism. Although different authors defined and conceptualized different types of stigma in varying ways, we found several scales and sub-scales of existing measures specifically designed to capture stigma among populations who are d/DHH (Patrick et al. 2011; Vincent et al. 2017; Mousley & Chaudoir 2018). From these identified studies, we created a pool of more than 200 survey items that captured different aspects of stigma.

Because of the diversity of people who are d/DHH, we designed the survey such that participants would initially self-identify or describe their hearing status (e.g., as deaf, Deaf, a person with hearing loss, hearing, hard of hearing, a parent of a child who is d/DHH, care partner, other, etc.). The text of the individual survey items would then

adapt to appropriately refer to the participant, based on how they self-identified. For example, for the item "*People are uncomfortable around me because …*," an individual who identified as "Deaf" might respond to "*People are uncomfortable around me because I am Deaf.*" The initial draft survey was specifically designed for populations who are d/DHH and included measures for different types of d/DHH stigma (experienced, perceived, anticipated, internalized), as well as stigma regarding hearing device usage, a measure of ageism (to be asked only of participants over the age of 60), and relevant contextual factors (sociodemographic, social identities, type of hearing loss, availability of care, communication preferences, and comorbidities). Through similar processes, complementary measures were created for parents, care partners, HCPs, and the general population from this initial draft of the survey, with the goal of identifying a core set of items that would, with slight variations, be appropriate across different populations and in different contexts to facilitate comparison of data across types of stigma (e.g. experience and perceived) and actors (those experiencing and those perpetrating stigma). Supplemental Digital Content 2 provides an overview of the number of items included in each stage of the survey development process for the lifelong d/DHH group.

Step 2: Modified Delphi Process

Between March and August 2021, we used a Modified Delphi Process to engage experts (e.g., researchers, clinicians, and individuals with lived experienced being d/DHH or caring for children who are d/DHH) with the measurement development process through a series of review meetings (Vincent et al. 2017; Niederberger & Spranger 2020). The Modified Delphi Process began with two rounds of internal review meetings with members of the LCHL Measures, Models, and Reduction of Stigma sub working group. Several team members then conducted eight external focus group discussion (FGD) meetings over Zoom with external experts and individuals with lived experience from 15 different countries. The participants included: people who are d/DHH (lifelong) (two groups with spoken communication as their main mode of communication), people who are d/DHH (acquired) (two groups), parents of children who are d/DHH (three groups); and researchers and clinicians who serve people who are d/DHH (one group). The LCHL helped identify these individuals through their various d/DHH networks of care providers and advocacy groups, connecting potential participants to the study team over email. A live, trained CART captioner provided on-screen captioning for all Zoom meetings. One additional in-person FGD meeting was held with individuals who are d/DHH (lifelong) and used Ghanaian Sign Language (GSL) as their main mode of communication, with GSL interpreters facilitating communication. Of note, we were unable to include people who are d/DHH (lifelong) from the U.S. who used sign language as their main mode of communication.

Modified Delphi Procedures—Each review meeting lasted approximately two hours. During both the review and FGD meetings, the participants were asked to consider the draft survey items, which had been divided into sections by type of stigma. Specifically, we asked the participants to reflect on the following three questions:

1. Do the proposed measures include the appropriate or relevant constructs or manifestations of stigma and discrimination under each type of stigma, or is anything missing?
2. Is the phrasing of the included statements for each construct understandable and contextually and culturally relevant?
3. How can the stigma measures be shortened? Can any constructs and/or statements be dropped?

The study team used the responses to the above questions and feedback from these discussions to assess the face validity of the proposed measures, and ultimately refine the wording of, add or remove survey items (Supplemental Digital File 2) (Leemans et al. 2015; Egger-Rainer 2019). The revisions were then further iteratively considered in subsequent FGD meetings. Following the completion of the Modified Delphi Process, the team finalized the revised survey items for the cognitive interviewing, the next step of mixed-methods validation.

Step 3: Cognitive Interviewing

From August through October 2021, cognitive interviews were conducted in the U.S. and Ghana to ensure that the survey items appropriately captured each type of stigma and were understood consistently as intended (Niederberger & Spranger 2020).The study team developed cognitive interview guides designed to elicit feedback regarding participant comprehension and interpretation of questions and that could be adapted and translated for each of the subpopulations recruited for the pre-test and main surveys. Participants were asked to respond to a set of stigma items for a specific type of stigma (e.g. experienced, perceived, internalized), and then were asked to consider the following questions for that set of items: (1) Did you have any difficulty with answering any of the questions?; (2) Which items were most important?; (3) Which items were least important?; and (4) Did any questions seem strange or inappropriate? Additionally, the interviewers were encouraged to ask further probing questions to the participants about why items were difficult, important, unimportant, or appropriate, as well as their reactions to the items. The cognitive interviewing procedures differed in each country, and leveraged available recruitment infrastructure while facilitating meaningful participation of target groups. Further, to operationalize recruitment into the d/DHH (lifelong) and d/DHH (acquired) groups, we developed screening criteria presented in Tables 2 and 3. In the U.S. recruitment was driven by age of onset (becoming d/DHH before or after age 3), while in Ghana (where age of onset is not always readily known), recruitment was driven by spoken language development (becoming d/DHH before or after spoken language development).

Ghana Cognitive Interviewing Procedures—In Ghana, 15 cognitive interviews were conducted in person with convenience samples of: (1) people who are d/DHH (lifelong) (n = 5); (2) people who are d/DHH (acquired) (n = 5); and (3) parents of children who are d/DHH (n = 5). (See Table 2 for inclusion/exclusion criteria). The populations of individuals who are d/DHH (lifelong) and parents of children who are DHH were recruited by study staff, with support from leadership within the Ghana National Association of the Deaf (GNAD). Recruitment was done through churches for people who are d/DHH and two schools for

children who are d/DHH in the Greater Accra and Eastern Regions that advertised the study and helped to identify participants. The population of individuals who are d/DHH (acquired) was recruited through three audiology clinics in the Greater Accra Region. Interviews with parents and individuals who are d/DHH (acquired) were conducted in English by trained hearing interviewers. The interviews were audio-recorded and transcribed. Members of the study team listened to the audio recordings of the first interviews and provided feedback to the interviewers, particularly about re-enforcing that the probing questions should be used to help explain how the participants understood the items and whether any words or phrases were confusing to them.

For the cognitive interviews with individuals who are d/DHH (lifelong), the surveys were delivered entirely in GSL instead of via written surveys because of low reading literacy and in preparation for the validation surveys. Experts from Gallaudet University in the U.S. provided training, guidance and expertise to the Ghanaian study team regarding the use of translation, consenting, and cognitive interviewing techniques. The Gallaudet University training included an overview of translating and consenting in a simplified language suitable for all people who are d/DHH (lifelong); a video demonstrating how to probe during a cognitive interview (Kushalnagar et al., 2017); and an overview of cognitive interviewing techniques for people who are d/DHH. The Ghanaian study team was led by a Ghanaian professor of GSL who is d/DHH and encompassed five other individuals fluent in GSL (four individuals who are d/DHH and one hearing interpreter). After the training, the Ghanaian study team translated the questions into GSL. For each item, the translation process consisted of many tasks. Each team member individually translated every question, the team discussed the contextual meaning of the individual item, and the team selected the translation that best captured the contextual meaning of the item. To ensure uniformity in the delivery of the questions across interviews, the study team filmed a single interviewer using GSL to sign each survey question and the response options. The videos were then shown to students and teachers at the Demonstration School for the Deaf, and when warranted, the videos were revised based on their feedback. When conducting the cognitive interviews, the interviewer (MN) used a tablet to play these videos to the participants. After each question the participant viewed on the tablet, the interviewer used GSL in-person to cognitive interview about the question the participant had just viewed. While we did not have ethics approval to video-record the GSL cognitive interviews, a notetaker attended the interviews to detail the participants' responses.

All Cognitive Interview participants were given 100 cedis (equivalent to $10 U.S. dollars) for participating, an amount adequate to compensate without coercing participation, given the lower standard income level in Ghana versus the U.S.

U.S. Cognitive Interviewing Procedures—In the *U.S.*, 30 one-on-one cognitive interviews were conducted with: (1) people who are d/DHH (lifelong) (n=5); (2) people who are d/DHH (acquired) (n=5); (3) the care partners of people who are d/DHH (n=5); (4) parents of children who are d/DHH (n=5); (5) HCPs who treat individuals who are d/DHH (n=5); and (6) the general population (n=5). (Table 3)

We contracted with L&E Research (New York, NY), a research firm that specializes in recruiting diverse populations through paid survey panels, to obtain convenience samples of n = 5 for three subgroups: individuals who are d/DHH (acquired); care partners of people who are d/DHH; and the general population. L&E Research disseminated an email invitation to its survey panels and screened participants who responded to the invitation to determine eligibility. Using a shared scheduling grid, the L&E Research recruitment official scheduled and confirmed the interview with the participant and trained interviewer. At least 24 hours before the interview, a calendar invitation, including a Zoom link; a consent form; and an electronic copy of the survey were sent to the participants, along with instructions to return the completed consent form before the interview.

The study team collaborated with consultants from the Duke University Department of Head and Neck Surgery and Communication Sciences and Alexander Graham Bell Association to conduct targeted recruitment for the remaining two subsamples: individuals who are d/DHH (lifelong) and parents of children who are d/DHH. The consultant pooled a network of families with children who are d/DHH and individuals to screen for interest and availability, then sent a personalized email invitation to potential participants explaining the study's purpose, the time commitment, and the compensation being offered. Participants who expressed interest to the consultant were referred to an interviewer who sent them a short screening questionnaire. Once their eligibility was confirmed, participants were sent the consent form, a questionnaire adapted for their respective subpopulation, and a calendar invitation with instructions on how to join the Zoom interview.

All interviews were conducted via Zoom, lasted between one and one and a half hours, and were audio recorded and then transcribed. When scheduling the interviews, we inquired about the specific communication needs of the potential participant. Ultimately, although some were fluent in American Sign Language (ASL), all participants preferred to be interviewed in English and, as such, we arranged for a trained CART captioner to provide captioning services for every interview with participants who were d/DHH (lifelong and acquired).

The interviews were divided into sections by type of stigma. During the interview, the interviewers prompted the participant to open and complete the fillable survey with the stigma items, instructing them to pause between each section. After each section was completed, the interviewers invited the participant to share their screen, thus showing how they responded to each item. The interviewers then commenced with the cognitive interview guide questions, asking probing questions when needed to obtain feedback about the participant's thought processes while answering, and so general survey improvements could be made. This process was repeated for each section of the questionnaire designed for the subpopulations. L&E Research distributed electronic gift cards for $125 (as is their standard practice for participation in this length of interview) to the participants who are d/DHH (acquired); to care partners of people who are d/DHH; and to the general population. RTI team members distributed electronic gift cards for $125 to participants who are d/DHH (lifelong) and to parents of children who are d/DHH. HCPs were not compensated for their time.

Cognitive Interviewing Analysis and Revision—A template was developed to guide the processing and analysis of the cognitive interviews and further assess the face validity of the measures (Leemans et al. 2015; Egger-Rainer 2019). Specifically, study team members read the transcripts and documented any difficulties the participants experienced with interpreting the questions, which items they considered to be the most important, and which ones were the least important. These findings were used to recommend modifications to the survey. The study team met to harmonize recommended modifications from the results of the U.S. and Ghanaian cognitive interviews and to ensure consistency in phrasing across the surveys for the different populations. Examples of revisions to the survey items are presented in Table 4.

Step 4: Pre-testing

After incorporating revisions and modifications from the cognitive interviews, we pretested the revised surveys in Ghana and the U.S., using different recruitment and survey methods. The pre-testing procedures differed by country, leveraging available recruitment infrastructure to access the target groups.

Ghana Pre-testing Procedures—In Ghana, the surveys were pretested in October 2021 with participants who are d/DHH (lifelong) (n = 30), individuals who are d/DHH (acquired) (n = 30), and parents of children who are d/DHH (n = 30). Of the people who are d/DHH (lifelong) pre-test group, 30% self-identified as hearing impaired, 33% as deaf, 23% as Deaf, and 13% as hard of hearing. Of the d/DHH (acquired) pre-test group, 43% self-identified as a person with hearing loss, 33% as hard of hearing, 17% as hearing impaired, 1% as hearing, and 1% as other.

The pretest surveys for participants who are d/DHH (lifelong) were conducted in-person in GSL by trained interviewers who are d/DHH, who played the pre-recorded videos of the questions and response options to participants, and then recorded the GSL survey responses on a pre-programmed tablet. For the pretest surveys for participants who are d/DHH (acquired) and for parents of children who are d/DHH, the survey was translated into Twi, Ga, and Ewe and reviewed by two research staff fluent in these languages. The surveys were conducted in-person by bi-lingual trained hearing interviewers in spoken English, Twi, Ga, or Ewe depending on the respondent's preference, and responses were recorded in English.

U.S. Pre-testing Procedures—In the U.S., six online, self-administered, written English surveys adapted for the six populations were pretested on convenience samples of roughly 30 participants per subgroup recruited during September and October 2021 using different recruitment methods. (Table 3) RTI subcontracted with Toluna (Dallas, Texas), which is a global research recruitment firm that pools participants from proprietary panels, to recruit four subgroups: people who are d/DHH (acquired) (n=33); care partners of people who are d/DHH (n=30); HCPs (n=32); and members of the general population (n=57). Of the d/DHH (acquired) pre-test group, 42% self-identified as a person with hearing loss, 27% as hearing impaired, 15% as hearing, 12% as hard of hearing, and 3% preferred not to answer the identity question. The HCPs that were recruited included audiologists; Medical Doctors

(MDs) specializing in ear, nose, and throat; and primary care providers, including MDs, physicians' assistants, and advanced practice nursing providers. For non-HCP samples, we excluded any participants who were healthcare workers to eliminate bias. The four groups recruited by Toluna completed an online screener prior to advancing to the survey. Upon completion of the survey, Toluna participants were compensated with digital rewards for completing invited survey opportunities.

For the populations of participants who are d/DHH (lifelong) (n=30) and parents of children who are d/DHH (n=28), the study team sent a promotional email containing the link to an online screener survey to a list of d/DHH family advocates associated with the Duke Hearing Center for Children and Families. Additionally, in 2021, the study team collaborated with Hearing Loss Association of America (HLAA) to recruit participants through HLAA's communication channels, including an e-blast message to HLAA membership on October 25; an article in HLAA's newsletter distributed on October 28; and social media posts about the opportunity during the week of October 25. All potential participants were directed to an online screener. Eligible participants were then sent the link to the self-administered, written English survey. Of the d/DHH (lifelong) pre-test group, 13% self-identified as person who is Deaf, 17% as deaf, 13% as hard of hearing, 7% as a person with hearing loss, 3% reported other, and 47% did not answer the identity question. To ensure that personally identifiable information was stored separately from survey responses, the last page of the survey rerouted the participants to an external survey link managed by Qualtrics in which they were prompted to enter an email address to receive compensation (i.e., a $25 electronic gift card). Gift cards were distributed via emails from the study team after verification to prevent fraudulent activity.

Pre-testing Analysis and Revision—Consistent with best survey practices, the pretest responses were inspected for timing, clarity of concepts, skipped items, variation in responses, and other potential issues that might introduce biases in the data. In Ghana, this pretest process helped identify technical challenges such as those involving video playback and skip patterns. For the video recorded interviews, this process also helped identify additional challenges with delivering the lifelong d/DHH survey, particularly related to the understanding of specific items and selecting from the response options.

Final Pre-tested Stigma Measures—The pre-testing analysis and revision culminated in the development of different measures of stigma for the following key groups: people who are d/DHH (lifelong); people who are d/DHH (acquired); parents of children who are d/DHH; healthcare providers; care partners of people who are d/DHH; and the general population. The final set of revised, pre-tested measures for each group – the result of the first four steps of the development process – can be found in Supplemental Digital Content 3-7.

Step 5: Psychometric Validation – Available in Subsequent Articles in this *Ear and Hearing* Supplement

The psychometric validation of each measure is presented in the articles in this supplement of *Ear and Hearing*. Table 5 outlines the scales presented in the subsequent manuscripts in

this special issue, that focus on populations who are d/DHH (Stelmach et al. this issue pp. XXXX), care partners of adults who are d/DHH (Wallhagen et al. this issue pp. XXXX), parents of children who are d/DHH (Saalim et al. this issue pp. XXXX), HCPs (Troutman Adams et al. this issue pp. XXXX), hearing device-related stigma (West et al. this issue pp. XXXX), and ageism (Nyblade et al. this issue pp. XXXX).

LIMITATIONS

There are some limitations inherent both to the measurement development exercise and to our methodological process. We first want to recognize that while a diverse group of researchers and experts from across the globe led this effort and engaged a wide array of individuals who are d/DHH in the modified Delphi process, we appreciate that it would have been valuable to have more thoroughly involved leaders and members of different d/DHH communities, in particular of the culturally Deaf community in the U.S. Further, this research may reflect a U.S. ethnocentric bias, given both the number of project leads from the U.S. and the choice of the U.S. as a data collection site to represent a high-income setting.

Second, due to resource and time constraints, we were unable to complete a scoping review adherent to PRISMA guidelines and only used one search engine (PubMed). Third, while we endeavored to create measures for a diverse group of individuals who are d/DHH, we focused only on adults, thus limiting our ability to measure stigma early in the life course, particularly during early childhood and adolescence. Fourth, the recruitment methods for both participants who are d/DHH (lifelong) and parents of children who are d/DHH may have introduced a bias towards the inclusion of participants who use spoken language as a primary or preferred mode of communication. Recognizing that Deaf individuals are likely to have a different experience with stigma than other groups who are d/DHH, efforts are needed to further assess these measures among the Deaf community. Fifth, we initially intended to develop anticipated stigma measures parallel to the experienced and perceived stigma measures. However, we ultimately cut these measures from the pre-test and validation surveys due to length and survey burden. Ultimately, we only include anticipated *hearing device* stigma measures the pre-test and validation surveys. Sixth, the experiences shared in the Modified Delphi process and all data we collected are subject to social desirability bias. Seventh, there may have been an opportunity for more rigorous integration of qualitative and quantitative findings throughout the sequential, mixed-method approach, particularly in interrogating and triangulating the findings from the psychometric assessments presented in the subsequent manuscripts. Eighth, only the Ghanian d/DHH lifelong sample received the survey in sign language.

Finally, with respect to generalizability, the sample sizes for the cognitive interviews were small. In the U.S., we only included literate English-speaking participants, limiting diversity, and held the interviews over zoom during COVID-19, which may have impacted participation. Further, in the U.S., while the use of a recruitment firm enabled access to the target population, the use of for-profit companies may have biased the sample, further limiting generalizability. In Ghana, we recruited participants who are d/DHH (acquired) from a clinical setting, limiting generalizability, and we were unable to film the cognitive

interviews with the population who are d/DHH (lifelong), which would have allowed for transcription of the interviews. As such, we had to rely on the notes taken during the interviews, and some of the details may have been missed. Again, the differing cognitive interviewing procedures may reflect an ethnocentric bias. Given the constrained scope of this project, these measures were ultimately tested in only two countries, and further research is necessary to understand whether these measures resonate globally. In particular, future assessment of these measures should account for cultural differences in attitudes towards aging and disability as well as for differences by collectivist versus individualistic societies.

CONCLUSION

We used a robust mixed-methods, exploratory sequential process to develop and conduct preliminary validation of measures of d/DHH stigma among three key groups in both the U.S. and Ghana, and an additional three populations in the U.S. Developing common measures of different types of stigma among such diverse populations, across cultures and income settings, was challenging, but yielded measures to assess various types of stigma. The psychometric assessments of these measures are described in the subsequent manuscripts in this supplement of *Ear and Hearing* (see Table 5 for details). We believe that these measures will support an empirical approach to studying d/DHH stigma and its effect on health. The resulting deeper understanding of stigma and its effect will facilitate improved clinical practice with respect to assessment, the rehabilitative process and addressing the individualized needs and goals of patients who are d/DHH. These measures will also allow for the development and evaluation of stigma-reduction interventions to increase health equity and promote greater health and well-being across the life course and in diverse cultural contexts. Future research should continue to assess the validity of these measures in other settings.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Financial disclosures/conflicts of interest:

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The data that support the findings of this study are openly available upon request to RTI International. Due to the nature of the data, it is publicly available after entering into a data sharing agreement with RTI International.

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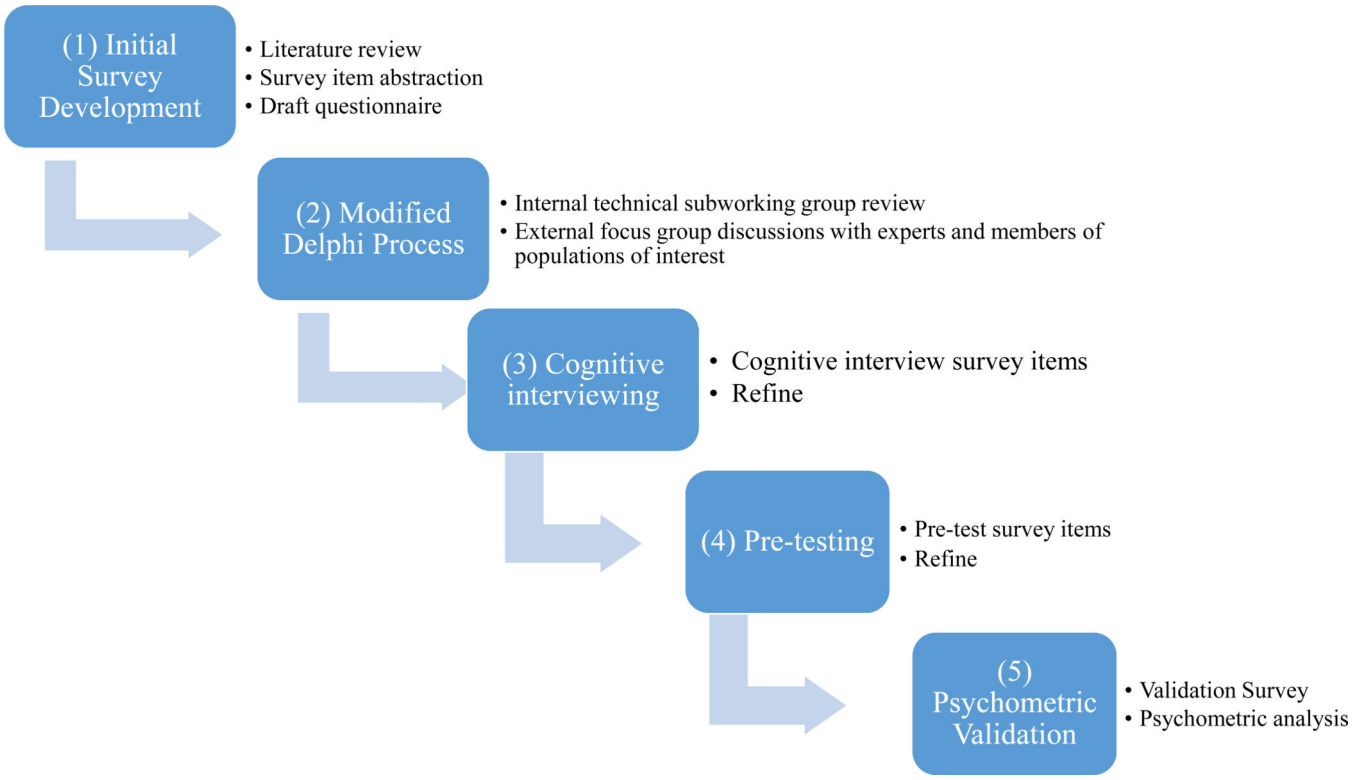

Figure 1:
Measurement Development Process: Joint Display

Table 1.

Definitions of the different types of stigma

Term	Definition	Examples	Citation
Stigma	A relational phenomenon that occurs within the context of power when a person possesses, or is thought to possess, attributes that suggest a condition or social identity that others consider to be of little value, abnormal, or undesirable in a particular social context	n/a	(Becker 1981; Crocker et al. 1998)
Experienced stigma	Stigma enacted through interpersonal acts of discrimination	Verbal or physical abuse, gossip, mistreatment	(Nyblade et al. 2021)
Perceived stigma	A stigmatized person's understanding of the prevalence of stigma and how people act toward those with the stigmatized condition or identity	Negative stereotypes, stigmatizing beliefs or attitudes	(Nyblade et al. 2021)
Internalized stigma	Stigma that the stigmatized accept as true and incorporate into their self-image (also known as self- or affiliative stigma)	Believing negative stereotypes apply to oneself	(Nyblade et al. 2021)
Anticipated stigma	The fear or expectation of stigma or discrimination	Worrying about how others will react to one's condition	(Nyblade et al. 2021)
Observed stigma	Hearing stories about or witnessing discrimination towards others (also known as witnessed stigma)	Seeing or hearing about the mistreatment of others	(Nyblade et al. 2021)
Secondary stigma	Stigma faced by people associated with stigmatized individuals or groups (also known as associative stigma, courtesy stigma, and third-party disability)	Stigmatization of friends, family, or care partners of the stigmatized individuals	(World Health Organization 2001)
Intersectional stigma	The convergence and amplification of stigma that occurs when a person belongs to multiple stigmatized groups	Stigmatization of individuals who are both D/deaf and older	(Turan et al. 2019; Sievwright et al. 2022)

Table 2.

Exclusion and inclusion criteria for Ghana cognitive interviews and surveys

Population	Inclusion	Exclusion
People who are d/DHH (lifelong)	• Is Ghanaian • Is aged 18 years or older • Has been d/DHH since birth or prior to speech • Is proficient in GSL	• Employed as an HCP
People who are d/DHH (acquired)	• Is Ghanian • Is aged 18 years or older • Became d/DHH in adulthood or after speech	• Employed as an HCP
Parents of children who are d/DHH	• Is Ghanian • Is aged 18 years or older • Is a parent of a child who has been d/DHH since early childhood	• Employed as an HCP • Child not yet in school

d/DHH = d/Deaf or hard of hearing; GSL = Ghanaian Sign Language; HCP = health care provider

Table 3.

Exclusion and inclusion criteria for U.S. cognitive interviews and surveys

Population	Inclusion	Exclusion
People who are d/DHH (lifelong)	• Is a U.S. resident • Is aged 18 years or older • Has Internet access with videoconferencing capabilities • Has been d/DHH since before 3 years of age • Is English literate	• Employed as an HCP
People who are d/DHH (acquired)	• Is a U.S. resident • Is aged 18 years or older • Has Internet access with videoconferencing capabilities • Has been d/DHH after 50 years of age (for the cognitive interviews) or after 3 years of age (for the pretest and surveys) • Is English literate	• Employed as an HCP
Parents of children who are d/DHH	• Is a U.S. resident • Is aged 18 years or older • Has Internet access with videoconferencing capabilities • Is a parent of a child who has been d/DHH since early childhood • Is English literate	• Employed as an HCP
Caregivers, of people who are d/DHH	• Is a U.S. resident • Is aged 18 years or older • Has Internet access with videoconferencing capabilities • Identifies as an unpaid caregiver to a person who is d/DHH (persons who are spouses, partners, children or relatives, or have another type of caregiving relationship with someone who is d/DHH) • Is English literate	• Employed as an HCP • Employed as a caregiver • Parents or guardian to children who are d/DHH and are aged 18 years or younger
HCPs	• Is employed in the United States as a Medical Doctor (MD, DO, advanced practice nurse, or physicians assistant) • Specializes in ear, nose, and throat; primary care practice; or audiology • Has Internet access with videoconferencing capabilities • Is English literate	• Does not treat individuals who have hearing loss or are d/DHH
General population	• Is a U.S. resident • Is aged 18 years or older • Has Internet access with videoconferencing capabilities • Is English literate	• Employed as an HCP • Is a caregiver, spouse, or partner of a person who is d/DHH • Parent of a person who is d/DHH

* d/DHH = d/Deaf or hard of hearing; DO = Doctor of Osteopathic Medicine; HCP = Health care provider; MD = Medical Doctor; US = United States

Table 4.

Revisions to survey items based on cognitive interviews

Original item	Participant feedback	Revised item
Someone became angry or frustrated with me because I am deaf or hard of hearing.	Participants who are d/DHH and their caregivers said that people rarely become "angry" with them because of their hearing loss; they experience frustration or "giving up" on the communication. The scale was revised to better account for frequency or commonality of the occurrences.	How often does someone become frustrated with you because you are d/Deaf or hard of hearing?
Someone stared at me.	Participants who are d/DHH and their caregivers did not think that this item was important, but offered that other acts, such as bullying or being taken advantage of, are more common.	How often are you bullied or taken advantage of because you are d/Deaf or hard of hearing?
Someone treated me unjustly.	"Unfairly" is a plain-language word and easier for some to interpret.	How often are you treated unfairly or unjustly by someone because you are d/Deaf or hard of hearing?
Someone was unwilling to talk or communicate with me.	Participants who are d/DHH noted that it is uncertain why some people are unwilling to communicate with them; they suggested specifying this question so that it focuses on instances when they know people are unwilling to talk to them because they are d/DHH.	How often is someone unwilling to talk or communicate with you because you are d/Deaf or hard of hearing?

*d/DHH = d/Deaf or hard of hearing

Table 5:

The Articles in the Special Issue From the Lancet Commission on Hearing Loss Measures, Models and Reduction of Stigma sub working group, With Brief Summaries

Bookend papers			
Subject	**Description**		**Citation**
Introduction	1) Provides an introduction and rationale for measuring stigma in the context of hearing loss and 2) Details the methods for developing, refining, and validating the measures presented in this supplemental issue		(Stockton et al. this issue pp. XXXX)
Conclusion	Outlines research agenda and future uses for scales		(Stelmach, Musa, et al. this issue pp. XXXX)
Preliminary psychometric validation papers			
Topic or population	**Scale**	**Type of stigma and population**	**Citation**
People with lived experience of being d/DHH	d/DHHS-LE-E	Experienced d/DHH stigma toward people who are d/DHH	(Stelmach, Stockton, et al. this issue pp. XXXX)
	d/DHHS-LE-P	Perceived d/DHH stigma toward people who are d/DHH	
	d/DHHS-LE-I	Internalized d/DHH stigma among people who are d/DHH	
Parents of people who are d/DHH	d/DHHS-P-OE	Parents' observations of stigma experienced by their children who are d/DHH	(Saalim et al. this issue pp. XXXX)
	d/DHHS-P-P	Parents' perceptions of stigma toward children who are d/DHH	
	d/DHHS-P-SE	Parents' experienced secondary stigma about being a parent of a child who is d/DHH	
	d/DHHS-P-SP	Parents' perceptions of secondary stigma toward themselves as a parent of a child who is d/DHH	
	d/DHHS-P-I	Internalized stigma among parents of children who are d/DHH	
Care partners of people who are d/DHH	d/DHHS-CP-O	Care partners' observations of stigma toward the person who is d/DHH for whom they care	(Wallhagen et al. this issue pp. XXXX)
	d/DHHS-CP-P	Care partners' perceptions of stigma toward people who are d/DHH	
	d/DHHS-CP-SE	Care partners' experienced secondary stigma about being a care partner of a person who is d/DHH	
	d/DHHS-CP-SP	Care partners' perceptions of stigma toward themselves as a care partner of a person who is d/DHH	
	d/DHHS-CP-SI	Secondary internalized stigma among care partners of people who are d/DHH	
Health care providers for people who are d/DHH	d/DHHS-HCP-SHPS	HCP's secondhand perceived stigma toward people who are d/DHH	(Troutman Adams et al. this issue pp. XXXX)
	d/DHHS-HCP-SHPE	HCP's secondhand perceptions of stigma experienced in health care settings by patients who are d/DHH	
	d/DHHS-HCP-HCPE	HCP-enacted d/DHH stigma	
Hearing device-related stigma	d/DHHS-LE-HDA	Anticipated hearing device-related stigma among people who are d/DHH and use hearing devices	(West et al. this issue pp. XXXX)
	d/DHHS-P-HDPO	Parents' perceptions and observations of hearing device-related stigma toward their child who is d/DHH and uses a hearing device	

Bookend papers			
Subject	**Description**		**Citation**
	d/DHHS-CP-HDPO	Care partners' perceptions and observations of hearing device-related stigma toward the person for whom they care who is d/DHH and uses a hearing device	
	d/DHHS-HCP-HDSH	HCP's secondhand observations of stigma associated with hearing device-related stigma	
Ageism	d/DHHS-LE-EA	Experienced ageism among people who are d/DHH	(Nyblade et al. this issue pp. XXXX)
	d/DHHS-CP-OA	Care partners' observations of ageism toward the person for whom they care who is d/DHH	
	d/DHHS-GP-OA	General population members' observations of ageism	
	d/DHHS-HCP-OA	HCP's observations of ageism in health care settings	

* d/DHH = d/Deaf or hard of hearing