Hearing Disability (v1) Definition Fact Sheet & Technical Brief

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<u>Definition Description</u>: The Hearing Disability (v1) definition is part of a group of eight definitions (seven domain-specific and one overall) to identify emergency department visits by people with disabilities using a set of criteria based on diagnostic codes, including ICD-9, ICD-10, SNOMED codes, and keywords representing patient reason for visit. These definitions can be used to disaggregate monitored health outcomes by disability status and type and will ultimately help improve emergency and ongoing surveillance efforts. We encourage National Syndromic Surveillance Program (NSSP) Community of Practice (CoP) members to work with disability organizations and members of the disability community within their jurisdictions when using the definitions, interpreting results, and developing recommendations based on these findings. This definition was tested and intended to run on the "CC and DD parsed free text" field in ESSENCE.

New or Revised Definition: New Definition

Date Added to ESSENCE: February 2025

<u>Use-Cases for Definition:</u> Case-finding: Not Intended as Use Case Trend monitoring: Primary Early outbreak detection: Not Intended as Use Case Emergent Condition: Not Intended as Use Case

<u>Justification for New Definition</u>: Information on disability status and type are not systematically collected during health encounters, and, as such, monitored health outcomes cannot currently be disaggregated by this demographic. Identifying people with disabilities using definitions for syndromic surveillance could bolster ongoing surveillance before, during, and after emergencies. It could also improve national, state, and local capacity to respond to, detect, understand, and monitor health events among people with disabilities during emergencies.

Data Source During Development: Emergency department visits

<u>Validation Methods</u>: The Association of State and Territorial Health Officials (ASTHO) worked collaboratively with CDC and the Council of State and Territorial Epidemiologists (CSTE)-led NSSP CoP to create diagnostic code-based definitions to identify emergency department visits from people with disabilities through a stakeholder-informed process. ASTHO, with support from Thought Bridge LLC, collected stakeholder feedback through a two-step process to inform the development of diagnostic code-and chief complaint-based definitions for disability to be used in NSSP. This two-step process included key informant interviews (KIIs) followed by five scientific panel sessions to inform definition development and broader dissemination efforts to promote uptake of the definitions. See Overall Disability (v1) Definition Fact Sheet & Technical Brief for a full description of definition development methods.

We used the following developed definitions from the CCW to develop the hearing domain. If only ICD-10 was available in a definition, we used the prior version for ICD-9:

Sensory - Deafness and Hearing Impairment

Using this initial set of codes, we abstracted relevant ICD-10 codes following inclusion criteria. Additional codes were collected from an ongoing project at the Massachusetts Department of Health, Office of Health Equity. Many of these codes overlapped with the existing CCW definition. Keywords were developed from feedback following the third and fourth scientific panels, and from keywords included in the Washington Group Short Set related to hearing. Following state and local pilot testing, we excluded additional terms and excluded specific ICD-10 codes that were leading to false positive results.

Important Analytic Note: If users plan to explore the co-occurrence of the Hearing Disability domain with the Specific Developmental or Learning Disability domain, revision of the keyword negations should be conducted as this domain includes "vision impaired" and "vision problems" whereas the Specific Developmental and Learning Disability domain excludes these as keywords.

A summary of documented changes made during each step of the development process is included in Table 3. We have also created an Excel sheet with all codes and chief complaints included in this definition as an appendix. The definition domain fact sheets offer versatile guidance, allowing users to employ them individually or collectively as a whole definition of disability based on the objectives of the jurisdiction. Utilizing the accompanying Excel sheets enables a comprehensive understanding of the conditions included within each domain.

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<u>Validation Results</u>: Jurisdictions found that this definition was broadly able to capture the intended cases. A few false positives were identified, as a result of misspellings, negations, and use of the word 'hear' in case text. The Hearing Disability (v1) definition was tested nationally and by three states: TN, GA, and CO. Jurisdictions partnering with CDC and ASTHO to pilot this definition saw a positive predictive value (PPV) of 87% for TN, 38% for GA, and 40% for CO. As a result of the validation process, all codes in the H66 and H61.2 ICD-10 list (same exclusions added for ICD-9 and SNOMED were added to exclusions, and exclusion variations were included for variations of 'HEAR' with 'VOICE', 'SOUND', 'NOISE', 'SCREAM', CRY', 'POP', 'WHEEZ', 'COUGH', misspellings due to the use of the word 'HEAR' instead of 'HERE', e.g. 'HEAR FOR DIALYSIS', and negations, such as 'DENIES ANY HEARING LOSS', 'NO LOSS OF HEARING'. As a result of the low jurisdiction PPV, validation was conducted again at the national level following final definition revisions. As part of national testing, 'EAR INFECTION' and 'IMPACTED CERUMEN' were added as negations. Following edits made following jurisdiction testing and the second round of national-level testing, PPV at the national level was 96.5%.

<u>Limitations</u>: This definition has some limitations, including some false positives that remain related to impacted cerumen, pulled in combination with general hearing loss codes such as unspecified hearing loss, bilateral hearing loss, etc. (though infrequently).

Additionally, there are at least five limitations common to the Overall Disability (v1) definition and all seven disability domain-specific definitions. First, identifying people with disabilities as a demographic using diagnostic codes follows a medical model of disability, and does not capture the social or identity-based aspects of disability preferred by many disability advocates. However, NSSP-ESSENCE is limited by the information routinely collected in the medical record such as diagnostic codes and notes captured as "chief complaint" to document presenting medical and relevant information for the visit. Future efforts to also include self- or other-report of functional disability collected as a demographic at the point of care may inform refinements to these definitions. Second, diagnostic codes do not map directly to functional limitations and a person may have more than one disability type, yet only discuss certain chief complaints during an ED visit. However, we can assume that certain conditions can be reasonably expected to produce functional limitations (e.g., someone with muscular dystrophy could reasonably be categorized as having a mobility disability). Third, coding practices can vary by region, hospital, and provider. Fourth, this method depends on factors outside the provider's control (billing considerations; EMR systems such as Epic or Cerner may have limits on how many dx codes can be listed under a visit). As a definition that is dependent on secondary diagnosis codes for detection not necessarily captured by the chief complaint, the ability to identify a person with a disability is influenced by the number of diagnosis codes a facility submits for syndromic surveillance. Therefore, this definition may be better able to identify people with disabilities in better resourced facilities, while data from lower cost EMR systems may be more likely to underrepresent the disability community. Fifth, many people with disabilities will be missed using this method as it relies on existing data collected on electronic health records (EHR), rather than standard self-reported questions that are commonly used to identify people with disabilities. People presenting to an emergency department for a health crisis or emergency may not have disability-related diagnoses indicated on their EHR, because their disability was not recognized by the provider and/or disclosed by the patient. Mild (or non-apparent) disabilities and/or disabilities unrelated to the reason for the ED visit may be more frequently under-documented than more apparent disabilities or those directly associated with the reason for visit.

The definitions can be used to identify important trends and serve as a "signal" of group variation for key outcomes of interest. However, NSSP users must be aware that results are likely an incomplete indicator of disability status or type. Despite limitations, these definitions can help serve as a stopgap to identify people with disabilities within NSSP-ESSENCE while we work collectively to address systemic issues related to collecting disability as a demographic at the point of care.

<u>Definition Fields and Structure</u>: Hearing-related disability, including unique chief complaint terms and diagnostic codes.

Detailed Definition Components

Table 1. Inclusion and exclusion terms based on a case definition using hearing disability-specific
discharge diagnosis codes, Hearing Disability (v1) definition

Variable Type	Terms	Description (Diagnosis Codes Only)
Inclusions		
Discharge	D33.3, H93.3	Acoustic euroma
Diagnosis:ICD-10- CM	G60.1	Refsum disease
	H81.0, H81.4	Disturbance of labyrinthine-vestibular function, Meniere's disease
	H90.0, H93.8,	Hearing loss, bilateral
	H93.93	
	H90.3	Sensorineural hearing loss, bilateral
	H90.4	Sensorineural hearing loss, unilateral with unrestricted hearing on the contralateral side
	H90.5	Unspecified sensorineural hearing loss
	H90.6	Mixed conductive and sensorineural hearing loss, bilateral
	H90.7	Mixed conductive and sensorineural hearing loss, unilateral with unrestricted hearing on the contralateral side
	H90.8	Mixed conductive and sensorineural hearing loss, unspecified
	H90.A21	Sensorineural hearing loss, unilateral, right ear, with restricted
		hearing on the contralateral side
	H90.A22	Sensorineural hearing loss, unilateral, left ear, with restricted hearing on the contralateral side
	H90.A31	Mixed conductive and sensorineural hearing loss, unilateral, right ear with restricted hearing on the contralateral side
	H90.A32	Mixed conductive and sensorineural hearing loss, unilateral, left ear with restricted hearing on the contralateral side
	H91.01	Ototoxic hearing loss, right ear
	H91.02	Ototoxic hearing loss, left ear
	H91.03	Ototoxic hearing loss, bilateral
	H91.09	Ototoxic hearing loss, unspecified ear
	H91.2	Sudden idiopathic hearing loss, NOS
	H91.3	Deaf nonspeaking NEC
	H91.8X1	Other specified hearing loss, right ear
	H91.8X2	Other specified hearing loss, left ear
	H91.8X3	Other specified hearing loss, bilateral
	H91.8X9	Other specified hearing loss, unspecified ear
	H91.9	Unspecified hearing loss
	H93.25	Auditory processing disorder
	Q16.0, Q16.1, Q16.2, Q16.3, Q16.4, Q16.5, Q16.9	Congenital malformations of ear causing impairment of hearing
	Z96.21	Cochlear implant status
Discharge	315.23	Auditory processing disorder
Diagnosis: ICD-9- CM	356.3	Refsum disease
	388.11	Other specified hearing loss
	389	Conductive and sensorineural hearing loss
	389.10	Unspecified sensorineural hearing loss
	389.11	Sensory hearing loss, bilateral
	389.12	Neural hearing loss, bilateral
	389.13	Neural hearing loss, unilateral
	389.14	Central hearing loss

	389.15	Sensorineural hearing loss, unilateral			
	389.15	Sensorineural hearing loss, unilateral, left ear, with restricted hearing			
	000.10	on the contralateral side			
	389.15	Sensorineural hearing loss, unilateral, right ear, with restricted			
	000.10	hearing on the contralateral side			
	389.16	Sensorineural hearing loss, asymmetrical			
	389.17	Sensory hearing loss, unilateral			
	389.18	Sensorineural hearing loss, bilateral			
	389.2	Mixed conductive and sensorineural hearing loss			
	389.7	Deaf nonspeaking NEC			
	389.8	Other specified forms of hearing loss			
	744	Congenital malformations of ear causing impairment of hearing			
		Acoustic neuroma			
	225.1, 388.5				
	386.00, 386.01, 386.02, 386.03,	Hearing loss, bilateral			
	386.04, 386.2				
Discharge	15188001	Other specified forms of hearing loss			
Diagnosis:-	15241006	Unspecified sensorineural hearing loss			
SNOMED concepts	25362006	Refsum's disease			
	77507001	Mixed hearing loss			
	79471008	Sudden idiopathic hearing loss, NOS			
	95820000	Hearing loss, bilateral			
	111339003	Congenital malformations of ear causing impairment of hearing			
	194424005	Central conductive, and sensorineural hearing loss			
	194429000	Mixed conductive and sensorineural hearing loss, bilateral			
	359612003	Cochlear implant status			
	427772009	Other specified hearing loss			
	126949007,	Acoustic neuroma			
	77949003				
	13445001,	Disturbance of labyrinthine-vestibular function, Meniere's disease			
	38403006, 20425006				
	15241006,	Sensory hearing loss, unilateral			
	427772009,				
	60700002,				
	95820000				
	229752008, 188061000119100	Auditory processing disorder			
	61947007,	Deaf nonspeaking NEC			
	788953003,				
	95821001				
	77507001, 95820000	Neural hearing loss, bilateral			
Chief Complaint		sign language ASL D/HH			
Terms	deaf, hearing impair, sign language, ASL, D/HH (trouble, hard, difficulty, impair, problem, loss, reduced) AND (hear)				
Exclusions					
Discharge	H66	Suppurative and unspecified otitis media			
Diagnosis:ICD-10-	H61.20, H61.21, H61.22, H61.23	Impacted cerumen			
см					
		Imported conumon			
Discharge	380.4	Impacted cerumen			
CM Discharge Diagnosis: ICD-9-	380.4 382.0, 382.1,	Impacted cerumen Suppurative and unspecified otitis media			
Discharge	380.4				

Discharge Diagnosis: SNOMED concepts	65363002	Suppurative and unspecified otitis media	
Chief Complaint Terms	heart, hear for dialysis, (denie, deny, no) AND (hear) AND (loss, problem), (voices, sound, noise, scream, cry, pop, wheez, cough) AND (hear), ear infection, impacted cerumen		

Plain Language Syntax Description: The Hearing Disability (v1) definition intends to identify emergency department visits by people with hearing-related disabilities. The definition includes diagnosis codes and words related to functional difficulty related to hearing. Users can combine the hearing definition with other definitions used to track important public health outcomes (e.g., heat-related illness, suicide attempts, or infection) to find out if emergency department visits for these important outcomes are more common among people with hearing-related disabilities compared to people without hearing-related disabilities. This definition will not capture everyone with a hearing-related disability, but it can be used to look at trends and help public health professionals better understand the impact of health concerns on the disability community. This information can be used to help make sure the needs of people with disabilities are considered and addressed when responding to health concerns.

Table 2. ESSENCE syntax, Hearing Disability (v1) Definition

This definition was tested and intended to run on the "CC and DD parsed free text" field in ESSENCE. Hearing Disability ICD9 0 (,^;389;^,or,^;389[278];^,or,^;389[1][0-9];^,or,^;38906;^,or,^;2251;^,or,^;2251[0-9];^,or,^;31523;^,or,^;3563;^,or,^;3563[0-9];^,or,^;386[02];^,or,^;386[02][0-9];^,or,^;388[2589];^,or,^;388[2589][0-9];^,or,^;38811;^,or,^;744;^,or,^;744[0-9];^,or,^;744[0-9][0-9];^,),ANDNOT,(,^;380.4;^,or,^;382[0-9];^,) ICD10 • (,^;D333^,or,^;G601^,or,^;H81[04]^,or,^;H90[03-0 8]^,or,^;H90A[23]^,or,^;H91[02389]^,or,^;H9325^,or,^;H933^,or,^;Q16[0-9]^,or,^;Z9621^,),ANDNOT,(,^;H66[012349]^,or,^;H612[0-3],) SNOMED (,^;79471008;^,or,^;427772009;^,or,^;60700002;^,or,^;229752008;^,or,^;194424005;^,or, 0 ^;61947007;^,or,^;13445001;^,or,^;359612003;^,or,^;111339003;^,or,^;15188001;^,or,^; 77507001;^,or,^;194429000;^,or,^;25362006;^,or,^;15241006;^,or,^;77949003;^,or,^;188 061000119100;^,or,^;788953003;^,or,^;38403006;^,or,^;95820000;^,or,^;126949007;^,or ,^;95821001;^,or,^;20425006;^,),ANDNOT,(,^;18070006;^,or,^;65363002;^,) All Together (,^;389;^,or,^;389[278];^,or,^;389[1][0-9];^,or,^;38906;^,or,^;2251;^,or,^;2251[0-0 9]:^,or,^:31523;^,or,^:3563;^,or,^:3563[0-9]:^,or,^:386[02]:^,or,^:386[02][0-9];^,or,^;388[2589];^,or,^;388[2589][0-9];^,or,^;38811;^,or,^;744;^,or,^;744[0-9];^,or,^;744[0-9][0-9];^,or,^;D333^,or,^;G601^,or,^;H81[04]^,or,^;H90[03-8]^,or,^;H90A[23]^,or,^;H91[02389]^,or,^;H9325^,or,^;H933^,or,^;Q16[0-9]^,or,^;Z9621^,or,^;79471008;^,or,^;427772009;^,or,^;60700002;^,or,^;229752008;^,or, ^;194424005;^,or,^;61947007;^,or,^;13445001;^,or,^;359612003;^,or,^;111339003;^,or,^ ;15188001;^,or,^;77507001;^,or,^;194429000;^,or,^;25362006;^,or,^;15241006;^,or,^;77 949003;^,or,^;188061000119100;^,or,^;788953003;^,or,^;38403006;^,or,^;95820000;^,or ,^;126949007;^,or,^;95821001;^,or,^;20425006;^,or,(,^deaf^,or,^hearing impair^,or,^sign language^,or,!ASL!,or,^D/HH^,or,(,^trouble^,or,^hard^,or,^difficulty^,or,^impair^,or,^probl em^,or,^loss^,or,^reduced^,),AND,(,^hear^,),),),ANDNOT,(,^;380.4;^,or,^;382[0-9]^,or,^;H66[012349]^,or,^;H612[0-3]^,or,^;18070006;^,or,^;65363002;^,or,^ear infection^,or,^impacted cerumen^,or,(,(,^voices^,or,^sound^,or,^noise^,or,^scream^,or,^cry^,or,^pop^,or,^wheez ^,or,^cough^,),AND,(,^hear^,),),or,^heart^,or,^hear for dialysis^,or,(,(,^denie^,or,^deny^,or,^no^,),AND,(,^hear^,),AND,(,^loss^,or,^problem^,),),)

Appendix

Definition Evolution During Development: Hearing Disability (v1)

Iteration 1: The first iteration of the definition included domains of Hearing, Vision, Mobility, IDD, and Cognition and Central Nervous System Disorders. This first definition was presented to the scientific panel.
General
 General The scientific panel suggested we capture more domains and conditions, like those included in disability policies like the Americans with Disabilities Act (ADA). As a result, we excluded conditions generally expected to last less than 6 months, those that can be treated surgically or through medication, and are acute or generally self-limiting conditions (e.g., conditions that do not result in functional impairments or limitations to
 daily life). We included additional domains for Self-care and Learning Mapped ICD-10 to ICD-9 where needed
Iteration 2: The second iteration was provided to the scientific panel for feedback and edits. The following changes were made:
Hearing
∘ None
Iteration 3: The third iteration was provided to the scientific panel for feedback and edits. The following changes were made:
General
 Added numerous keywords provided during breakout sessions of the scientific panel
Iteration 4: Following the third scientific panel, CDC pilot-tested the definition at the national level. The following changes were made:
General
 Added key chief complaint terms discussed during the panel meeting to each domain
Iteration 5: Following state and local pilot testing of the definition, the following changes were made:
Hearing
 Suggestion to exclude codes for ear infections (otitis media) H66.9[123] and H61.2[123].
 Decided to exclude all codes in the H66 and H61.2 ICD-10 list (same exclusions added for ICD-9 and SNOMED.
 Suggestion to determine if H81.09^MENIERE'S DISEASE UNSPECIFIED EAR or visits related to ear infection or impacted cerumen should remain included. Decided to keep code H81.0 due to lifelong nature of condition but excluded impacted cerumen (H61.2).
 Cleaned up ICD-9, ICD-10, and SNOMED of duplicate codes in Excel sheet. Added suggestions for exclusions and variations to keywords including:
 Variations of 'HEAR' with 'VOICE', 'SOUND', 'NOISE', 'SCREAM', CRY', 'POP', 'WHEEZ', 'COUGH'. Misspellings due to the use of the word 'HEAR' instead of 'HERE', e.g. 'HEAR
FOR DIALYSIS'.
 Negations, such as 'DENIES ANY HEARING LOSS', 'NO LOSS OF HEARING'
Iteration 6: Following feedback from the fourth scientific panel, the following changes were made:
General

 Description for how keywords were collected and references to the Washington Group Short Set were added to each relevant fact sheet

Iteration 7: CDC conducted additional round of pilot testing of the definition at the national level to address concerns with inconsistent and/or low PPVs at the state and local level. Due to the scope of proposed revisions as described below, the definition development team decided to hold an ad-hoc fifth scientific panel meeting in May 2024.

- Hearing
 - Suggested to add exclusions for chief complaints "ear infection" and "impacted cerumen" as many false positives were associated with these chief complaints were observed.

Iteration 8: Following the fifth and final scientific panel, the following changes were made:

- Hearing
 - Added exclusions for chief complaints 'EAR INFECTION' and "IMPACTED CERUMEN" as many false positives associated with these chief complaints were observed.

Note: Table includes revisions for hearing domain only. See Overall Disability (v1) Definition Fact Sheet & Technical Brief for a full list of revisions.