

Self-Care and Independent Living Disability (v1)

Definition Fact Sheet & Technical Brief

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Definition Description: The Self-Care and Independent Living 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

Use-Cases for Definition:

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

Justification: Information on disability status and type are not systematically collected during emergency department visits, 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 living with disabilities during emergencies.

Data Source During Development: Emergency department visits

Validation Methods: 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.

The Self-Care and Independent Living domain was developed following the second scientific panel and using keywords found in the ADA for limitations to instrumental activities of daily living. This domain ensures the definition casts a wide net to describe all the ways disability can impact a person's daily living activities. The Self-Care and Independent Living domain captures a subset of visits with coding for disabilities not captured elsewhere that impact a person's daily living activities. This domain is Z-code based, which includes codes for environmental, social, and disorder agnostic symptoms a patient may display during a visit. The code list includes limitations of activities due to disability, need for assistance for personal care or for continuous supervision, and problems related to independent living or daily living. Keywords regarding Self-Care and Independent Living from the ADA and associated amendments, as well as the Washington Group Short Set descriptions include limitation of activities, activity impairment, life management difficulty, self-care assistance, difficulty caring for oneself, among others. While this domain is shorter than the other domains, it provides a critical and important piece of describing disability that is not traditionally captured in diagnostic code-based definitions.

Following state and local pilot testing, we excluded additional terms and excluded specific ICD-10 codes that were leading to false positive results.

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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Validation Results: Jurisdictions felt that the initial version of this definition may not broadly be able to capture the intended cases. Ruled out cases presented with codes for 'other reduced mobility' or 'personal risk factors, not otherwise classified' and the cases did not meet the criteria for disability. The Self-Care and Independent Living Disability (v1) definition was tested nationally and by two states: CA and IL. CA tested this definition using data from only one local health jurisdiction that is onboarded as a site in BioSense. CA has 61 local health jurisdictions. Jurisdictions partnering with CDC and ASTHO to pilot this definition saw a positive predictive value (PPV) of 100% for CA and 96% for IL. Based on validation testing feedback, revisions were made to the definition to exclude trouble breathing or difficulty breathing and without difficulty denies difficulty, remove "trouble eating" as term for inclusion, and removal of Z7409 and Z9189. Following state and local pilot testing of the definition, the following changes were made including, adding negations for trouble breathing or difficulty breathing and without difficulty denies difficulty, removal of "trouble/hard/difficulty eating" and "drinking" from list of key words, and adding code for "Person encountering health services to consult on behalf of another person", (Z71.0) to align with chief complaint field keywords. Following the fifth and final scientific panel, the following changes were made including, changing the title of domain name to include Independent Living and adding the code for "Adult Failure to Thrive" (R62.7). Following edits made following jurisdiction testing and the second round of national-level testing, PPV at the national level was 95.5%.

Limitations: This definition has some limitations, including some false positives that remain (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.

Definition Fields and Structure: Self-Care and Independent Living-related Disability; includes unique chief complaint terms and unique diagnostic codes.

Detailed Definition Components

Table 1. Inclusion and exclusion terms based on a case definition using specific discharge diagnosis codes, Self-Care and Independent Living Disability (v1) definition

Variable Type	Terms	Description (Diagnosis Codes Only)
Inclusions		
Discharge Diagnosis: ICD-10- CM	R46.0, Z91.89	Personal hygiene
	Z59.3	Problems related to living in residential institution
	Z60.2	Problems related to living alone
	Z71.0	Person encountering health services to consult on behalf of another person
	Z73.6	Limitation of activities due to disability
	Z73.8	Other problems related to life management difficulty
	Z74.1, Z74.09	Need for assistance with personal care
	Z74.2	Need for assistance at home and no other household member able to render care
Discharge Diagnosis: ICD-9- CM	Z74.3	Need for continuous supervision
	N/A	N/A
	105507009	Need for continuous supervision
	271437004	Problems related to living alone

Discharge Diagnosis code – SNOMED	413298002	Limitation of activities due to disability
	288521000119101	Other problems related to life management difficulty
	15929301000119104	Problems related to living in residential institution
	15936341000119106, 160685001	Need for assistance with personal care
	410428008, 281694009	Personal hygiene
Chief Complaint Terms	(trouble, hard, difficulty, impair, problems, deficit, unable, failure, concern, poor) AND (looking after self, managing medications, managing meds, dressing, caring for body parts, bathing, doing housework, preparing meals, self-care, selfcare, taking care, domestic life activities , eating, washing , eating , drinking, assisting others, caring for household, toileting, performing manual tasks, performing tasks, life management, living alone, residential institution, getting around inside home, ADL, housework), (,need, require, depend) AND (assistance, supervision, caregiver, caretaker, on others, attendant, PCA, guardian), (with, has, presents with, presents to ED with) AND (caretaker, guardian, PCA), guardianship, activity impairment, limitation of activities	
Exclusions		
Chief Complaint Terms	trouble breathing, difficulty breathing, without difficulty, denies difficulty	

Plain Language Syntax Description: The Self-Care and Independent Living Disability (v1) definition intends to identify emergency department visits by people with disabilities related to self-care or independent living. The definition includes diagnosis codes and words related to functional difficulty related to self-care (such as dressing or bathing) and independent living (such as doing errands alone or visiting a doctor's office). Users can combine the Self-Care and Independent Living Disability (v1) 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 disabilities related to self-care or independent living compared to people without disabilities related to self-care or independent living. This definition will not capture everyone with a disability related to self-care or independent living, 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, Self-Care and Independent Living Disability (v1) Definition

This definition was tested and intended to run on the "CC and DD parsed free text" field in ESSENCE.	
Self-Care and Independent Living	
• ICD9	o N/A
• ICD10	o ^;R460^,or,^;Z593^,or,^;Z602^,or,^;Z73[68]^,or,^;Z74[123]^,or,^;Z7409^,or,^;Z710^
• SNOMED	o ^;413298002^,or,^;288521000119101^,or,^;15936341000119100^,or,^;15936341000119106^,or,^;105507009^,or,^;410428008^,or,^;271437004^,or,^;15929301000119104^,or,^;160685001^,or,^;281694009^,or,^
• All Together	o ^;R460^,or,^;Z593^,or,^;Z602^,or,^;Z73[68]^,or,^;Z74[123]^,or,^;Z7409^,or,^;Z710^,or,^;413298002^,or,^;288521000119101^,or,^;15936341000119100^,or,^;15936341000119106^,or,^;105507009^,or,^;410428008^,or,^;271437004^,or,^;15929301000119104^,or,^;160685001^,or,^;281694009^,or,^,(,^(,^(trouble^,or,^hard^,or,^difficulty^,or,^impaired^,or,^problems^,or,^deficit^,or,^unable^,or,^failure^,or,^concern^,or,^poor^),),AND,(,^(looking after self^,or,^managing medications^,or,^managing meds^,or,^dressing^,or,^caring for body parts^,or,^bathing^,or,^doing housework^,or,^preparing meals^,or,^self care^,or,^selfcare^,or,^taking care^,or,^domestic life activities^,or,^washing^,or,^assisting others^,or,^caring for household^,or,^toileting^,or,^performing manual tasks^,or,^performing tasks^,or,^life management^,or,^living alone^,or,^residential institution^,or,^getting around inside home^,or,^!ADL!,or,^housework^),),or,^(,^(need^,or,^require^,or,^depend^),),AND,(,^assistance^,or,^supervision^,or,^caregiver^,or,^caretaker^,or,^on others^,or,^attendant^,or,^PCA!,or,^guardian^),),or,^(,^(with^,or,^has^,or,^presents with^,or,^presents to ED with^),),AND,(,^caretaker^,or,^guardian^,or,^!PCA!,),),or,^guardianship^,or,^activity impairment^,or,^limitation of activities^),ANDNOT,(,^(trouble breathing^,or,^difficulty breathing^,or,^without difficulty^,or,^denies difficulty^,or,^Spanish assistance req^),)

Appendix

Definition Evolution During Development: Self-Care and Independent Living Disability (v1)

<p>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.</p> <ul style="list-style-type: none">• General<ul style="list-style-type: none">○ 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
<p>Iteration 2: The second iteration was provided to the scientific panel for feedback and edits. The following changes were made:</p> <ul style="list-style-type: none">• Self-Care<ul style="list-style-type: none">○ None
<p>Iteration 3: The third iteration was provided to the scientific panel for feedback and edits. The following changes were made:</p> <ul style="list-style-type: none">• General<ul style="list-style-type: none">○ Added numerous keywords provided during breakout sessions of the scientific panel
<p>Iteration 4: Following the third scientific panel, CDC pilot-tested the definition at the national level. The following changes were made:</p> <ul style="list-style-type: none">• General<ul style="list-style-type: none">○ Added key chief complaint terms discussed during the panel meeting to each domain
<p>Iteration 5: Following state and local pilot testing of the definition, the following changes were made:</p> <ul style="list-style-type: none">• Self-care<ul style="list-style-type: none">○ Suggestion to exclude “trouble breathing”, “difficulty breathing”, “without difficulty” and “denies difficulty”.<ul style="list-style-type: none">▪ Added negations for “trouble breathing”, “difficulty breathing”, “without difficulty” and “denies difficulty”.○ Reviewed and considered "Eating" as term for inclusion. There were matches because of acute GI / NVD illness that are associated with trouble/problems eating or drinking that are not a disability.<ul style="list-style-type: none">▪ Removed trouble/hard/difficulty eating and drinking from list of key words○ Added code for Person encountering health services to consult on behalf of another person, Z71.0 to align with chief complaint field keywords.
<p>Iteration 6: Following feedback from the fourth scientific panel, the following changes were made:</p> <ul style="list-style-type: none">• General<ul style="list-style-type: none">○ Description for how keywords were collected and references to the Washington Group Short Set were added to each relevant fact sheet
<p>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.</p> <ul style="list-style-type: none">• Self-care

- Suggested to change title of domain name to Self-care and Independent Living. In addition to self-care, diagnostic codes included in this definition also include independent living (e.g., Problems related to living alone and problems related to living in residential institution).
- Suggested to add Adult Failure to Thrive (R62.7) as this code is often used in combination with other codes included under this domain. Defined as progressive functional deterioration of a physical and cognitive nature. The individual's ability to live with multisystem diseases, cope with ensuing problems, and manage their care are remarkably diminished.

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

- Self-Care and Independent Living
 - Changed title of domain name to Self-care and Independent Living
 - Added Adult Failure to Thrive (R62.7)

Note: Table includes revisions for self-care and independent living domain only. See Overall Disability (v1) Definition Fact Sheet & Technical Brief for a full list of revisions.