Intellectual and Developmental Disability (v1) Definition Fact Sheet & Technical Brief

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<u>Definition Description</u>: The Intellectual and Developmental 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</u>: 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 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 Disability (v1) – Disability Overall 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 intellectual and developmental disability domain. If only ICD-10 was available in a definition, we used the prior version for ICD-9:

- Autism Spectrum Disorders
- <u>Cerebral Palsy</u>
- Intellectual Disabilities and Related Conditions
- Other Developmental Delays
- ADHD, Conduct Disorders, and Hyperkinetic Syndrome

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, a CDC project for identifying adults with intellectual and developmental disabilities, and three research papers by <u>McDermott et al. (2018)</u>, <u>Phillips et al. (2018)</u>, and <u>Larson et al. (2001)</u>.

The scientific panel had many discussions about separating the intellectual and developmental disability domain into two. The group was split on whether this domain should be separated into one domain for intellectual disabilities and another for developmental disabilities or remain together. Ultimately, the definition team decided not to split these domains to best align with current categorization of these disabilities. Additionally, separating this domain would require extensive conversations with healthcare providers, disability experts, and people with lived experience and have broad implications beyond NSSP. This process would be lengthy and require further programming that the definition team did not have at this time.

Following state and local pilot testing, we excluded additional terms and excluded specific ICD-10 codes that were leading to false positive results. We examined the list of codes in the Intellectual and Developmental Disability and Specific Developmental Behavioral and Learning Disability domain and made sure codes were in the appropriate location given scientific panel feedback.

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 older patients experiencing cognitive issues from stroke or age, not due to disability. The Intellectual and Developmental Disability (v1) definition was tested nationally and by one state: AZ, which saw a positive predictive value (PPV) of 83%. As a result of the validation process, the Learning domain was renamed to "Specific Developmental and Learning" and codes

for ADHD, conduct disorders and hyperkinetic syndromes were moved from Intellectual and Developmental Disability to Specific Developmental, Behavioral, and Learning Disability. These codes include all codes under 312, 314 (ICD9), F63, F90, F91 (ICD10), and 66347000, 406506008, 430909002 (SNOMED). Codes for Lambert-Eaton syndrome (G70.00, G70.01, G70.1, G70.2, G70.80, G70.81, G70.89, G70.9) were moved from Intellectual and Developmental Disability to Chronic domain. In addition, specific developmental disorder of motor function, F82, was removed from Intellectual and Developmental Disability as it is represented in the Specific Developmental Behavioral and Learning Disability domain and would not be expected to be used in isolation for individuals with more comprehensive disabilities included under Intellectual and Developmental Disability, per emergency physician consultation. Following edits made following jurisdiction testing and the second round of national-level testing, PPV at the national level was 100%.

<u>Limitations</u>: This definition has some limitations, including some false positives that remain (though infrequently). This definition is also limited in that it was only tested by one jurisdiction; however, the definition performed well (i.e., high PPV) at the national level. While we ultimately decided to combine intellectual disability (ID) and developmental disability (DD) into a single domain, data users should be aware that while individuals with ID are considered to have a DD, those with DD may not have ID.

Diagnostic codes associated with Intellectual and Developmental Disability and Specific Developmental, Behavioral, and Learning Disability domains may be applied differently for children and adults; therefore, data users should be aware that certain codes may be more or less frequently used depending on age. Examples are developmental disorders that are more commonly diagnosed in school-aged children, such as learning disabilities (dyslexia, dyscalculia, dysgraphia, etc.), attention-deficit/hyperactivity disorder (ADHD), and behavioral disorders such as conduct disorder. Intellectual disability may also not be clinically recognized, particularly among adults, depending on the severity or underlying cause (see <u>Patel</u> <u>et al., 2020</u>).

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>: Intellectual and Developmental Disability, unique chief complaint terms and unique diagnostic codes not captured elsewhere (to be tested at state & local level)

Detailed Definition Components

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

Variable Type	Terms	Description (Diagnosis Codes Only)
Inclusions		
Discharge	E03.0, E03.1	Congenital hypothyroidism
Diagnosis:	E70	Disorders of aromatic amino-acid metabolism
ICD-10-CM	E70.0, E70.1	Phenylketonuria (PKU)
	E70.2	Disorders of tyrosine metabolism
	E70.20	Disorder of tyrosine metabolism, unspecified
	E70.21	Tyrosinemia
	E70.29	Other disorders of tyrosine metabolism
	E70.3	Albinism
	E70.30	Albinism, unspecified
	E70.31	Ocular albinism
	E70.310	X-linked ocular albinism
	E70.311	Autosomal recessive ocular albinism
	E70.318	Other ocular albinism
	E70.319	Ocular albinism, unspecified
	E70.32	Oculocutaneous albinism
	E70.320	Tyrosinase negative oculocutaneous albinism
	E70.321	Tyrosinase positive oculocutaneous albinism
	E70.328	Other oculocutaneous albinism
	E70.329	Oculocutaneous albinism, unspecified
	E70.33	Albinism with hematologic abnormality
	E70.330	Chediak-Higashi syndrome
	E70.331	Hermansky-Pudlak syndrome
	E70.338	Other albinism with hematologic abnormality
	E70.339	Albinism with hematologic abnormality, unspecified
	E70.39	Other specified albinism
	E70.4	Disorders of histidine metabolism
	E70.40	Disorders of histidine metabolism, unspecified
	E70.41	Histidinemia
	E70.49	Other disorders of histidine metabolism
	E70.5	Disorders of tryptophan metabolism
	E70.8	Other disorders of aromatic amino-acid metabolism
	E70.81	Aromatic L-amino acid decarboxylase deficiency

E70.89	Other disorders of aromatic amino-acid metabolism
E70.9	Disorder of aromatic amino-acid metabolism, unspecified
E71	Disorders of branched-chain amino-acid metabolism and fatty- acid metabolism
E71.0	Maple-syrup-urine disease
E71.1	Other disorders of branched-chain amino-acid metabolism
E71.11	Branched-chain organic acidurias
E71.110	Isovaleric acidemia
E71.111	3-methylglutaconic aciduria
E71.118	Other branched-chain organic acidurias
E71.12	Disorders of propionate metabolism
E71.120	Methylmalonic acidemia
E71.121	Propionic acidemia
E71.128	Other disorders of propionate metabolism
E71.19	Other disorders of branched-chain amino-acid metabolism
E71.2	Disorder of branched-chain amino-acid metabolism, unspecified
E71.3	Disorders of fatty-acid metabolism
E71.30	Disorder of fatty-acid metabolism, unspecified
E71.31	Disorders of fatty-acid oxidation
E71.310	Long chain/very long chain acyl CoA dehydrogenase deficiend
E71.311	Medium chain acyl CoA dehydrogenase deficiency
E71.312	Short chain acyl CoA dehydrogenase deficiency
E71.313	Glutaric aciduria type II
E71.314	Muscle carnitine palmitoyltransferase deficiency
E71.318	Other disorders of fatty-acid oxidation
E71.32	Disorders of ketone metabolism
E71.39	Other disorders of fatty-acid metabolism
E71.4	Disorders of carnitine metabolism
E71.40	Disorder of carnitine metabolism, unspecified
E71.41	Primary carnitine deficiency
E71.42	Carnitine deficiency due to inborn errors of metabolism
E71.43	latrogenic carnitine deficiency
E71.44	Other secondary carnitine deficiency
E71.440	Ruvalcaba-Myhre-Smith syndrome
E71.448	Other secondary carnitine deficiency
E71.5	Peroxisomal disorders
E71.50	Peroxisomal disorder, unspecified
E71.51	Disorders of peroxisome biogenesis
E71.510	Zellweger syndrome
E71.511	Neonatal adrenoleukodystrophy
E71.518	Other disorders of peroxisome biogenesis
E71.52	X-linked adrenoleukodystrophy
E71.520	Childhood cerebral X-linked adrenoleukodystrophy
E71.521	Adolescent X-linked adrenoleukodystrophy
E71.522	Adrenomyeloneuropathy
E71.528	Other X-linked adrenoleukodystrophy

E71.529	X-linked adrenoleukodystrophy, unspecified type
E71.53	Other group 2 peroxisomal disorders
E71.54	Other peroxisomal disorders
E71.540	Rhizomelic chondrodysplasia punctata
E71.541	Zellweger-like syndrome
E71.542	Other group 3 peroxisomal disorders
E71.548	Other peroxisomal disorders
E72	Other disorders of amino-acid metabolism
E72.0	Disorders of amino-acid transport
E72.00	Disorders of amino-acid transport, unspecified
E72.01	Cystinuria
E72.02	Hartnup's disease
E72.03	Lowe's syndrome
E72.04	Cystinosis
E72.09	Other disorders of amino-acid transport
E72.1	Disorders of sulfur-bearing amino-acid metabolism
E72.10	Disorders of sulfur-bearing amino-acid metabolism, unspecif
E72.11	Homocystinuria
E72.12	Methylenetetrahydrofolate reductase deficiency
E72.19	Other disorders of sulfur-bearing amino-acid metabolism
E72.2	Disorders of urea cycle metabolism
E72.20	Disorder of urea cycle metabolism, unspecified
E72.21	Argininemia
E72.22	Arginosuccinic aciduria
E72.23	Citrullinemia
E72.29	Other disorders of urea cycle metabolism
E72.3	Disorders of lysine and hydroxylysine metabolism
E72.4	Disorders of ornithine metabolism
E72.5	Disorders of glycine metabolism
E72.50	Disorder of glycine metabolism, unspecified
E72.51	Non-ketotic hyperglycinemia
E72.52	Trimethylaminuria
E72.53	Primary hyperoxaluria
E72.59	Other disorders of glycine metabolism
E72.8	Other specified disorders of amino-acid metabolism
E72.81	Disorders of gamma aminobutyric acid metabolism
E72.89	Other specified disorders of amino-acid metabolism
E72.9	Disorder of amino-acid metabolism, unspecified
E74	Other disorders of carbohydrate metabolism
E74.0	Glycogen storage disease
E74.00	Glycogen storage disease, unspecified
E74.01	von Gierke disease
E74.02	Pompe disease
E74.03	Cori disease
E74.04	McArdle disease
E74.09	Other glycogen storage disease
E74.1	Disorders of fructose metabolism

E74.10	Disorder of fructose metabolism, unspecified
E74.11	Essential fructosuria
E74.12	Hereditary fructose intolerance
E74.19	Other disorders of fructose metabolism
E74.2	Disorders of galactose metabolism
E74.20	Disorders of galactose metabolism, unspecified
E74.21	Galactosemia
E74.29	Other disorders of galactose metabolism
E74.3	Other disorders of intestinal carbohydrate absorption
E74.31	Sucrase-isomaltase deficiency
E74.39	Other disorders of intestinal carbohydrate absorption
E74.4	Disorders of pyruvate metabolism and gluconeogenesis
E74.8	Other specified disorders of carbohydrate metabolism
E74.81	Disorders of glucose transport, not elsewhere classified
E74.810	Glucose transporter protein type 1 deficiency
E74.818	Other disorders of glucose transport
E74.819	Disorders of glucose transport, unspecified
E74.89	Other specified disorders of carbohydrate metabolism
E74.9	Disorder of carbohydrate metabolism, unspecified
E75	Disorders of sphingolipid metabolism and other lipid storage disorders
E75.0	GM2 gangliosidosis
E75.00	GM2 gangliosidosis, unspecified
E75.01	Sandhoff disease
E75.02	Tay-Sachs disease
E75.09	Other GM2 gangliosidosis
E75.1	Other and unspecified gangliosidosis
E75.1	Other gangliosidosis
E75.10	Unspecified gangliosidosis
E75.11	Mucolipidosis IV
E75.19	Other gangliosidosis
E75.2	Other sphingolipidosis
E75.21	Fabry (-Anderson) disease
E75.22	Gaucher disease
E75.23	Krabbe disease
E75.24	Niemann-Pick disease
E75.240	Niemann-Pick disease type A
E75.241	Niemann-Pick disease type B
E75.242	Niemann-Pick disease type C
E75.243	Niemann-Pick disease type D
E75.244	Niemann-Pick disease type A/B
E75.248	Other Niemann-Pick disease
E75.249	Niemann-Pick disease, unspecified
E75.25	Metachromatic leukodystrophy
E75.26	Sulfatase deficiency
E75.29, E75.4	Cerebral Degenerations Manifest in Childhood
E75.3	Sphingolipidosis, unspecified

E75.5	Other lipid storage disorders
E75.6	Lipid storage disorder, unspecified
E76	Disorders of glycosaminoglycan metabolism
E76.0	Mucopolysaccharidosis, type I
E76.01	Hurler's syndrome
E76.02	Hurler-Scheie syndrome
E76.03	Scheie's syndrome
E76.1	Mucopolysaccharidosis, type II
E76.2	Other mucopolysaccharidoses
E76.21	Morquio mucopolysaccharidoses
E76.210	Morquio A mucopolysaccharidoses
E76.211	Morquio B mucopolysaccharidoses
E76.219	Morquio mucopolysaccharidoses, unspecified
E76.22	anfilippo mucopolysaccharidoses
E76.29	Other mucopolysaccharidoses
E76.3	Mucopolysaccharidosis, unspecified
E76.8	Other disorders of glucosaminoglycan metabolism
E76.9	Glucosaminoglycan metabolism disorder, unspecified
E77	Disorders of glycoprotein metabolism
E77.0	Defects in post-translational modification of lysosomal enzym
E77.1	Defects in glycoprotein degradation
E77.8	Other disorders of glycoprotein metabolism
E77.9	Disorder of glycoprotein metabolism, unspecified
E78.71	Barth syndrome
E78.72	Smith-Lemli-Opitz syndrome
E79.1	Lesch Nyhan syndrome
F70.0, F70.1, F70.8, F70.9	Mild intellectual disabilities
F71.0, F71.1, F71.8, F71.9	Moderate intellectual disabilities
F72.0, F72.1, F72.8, F72.9	Severe intellectual disabilities
F73.0, F73.1, F73.8, F73.9	Profound intellectual disabilities
F78.0, F78.1, F78.8, F78.9,	Other intellectual disabilities
F78.A, F78.A1, F78.A9 F79.0, F79.1, F79.8, F79.9	Unspecified intellectual disabilities
F84	Pervasive developmental disorders
F84.0	Autistic Disorder
F84.1	Atypical autism
F84.2	Rett's syndrome
F84.3	Other childhood disintegrative disorder
F84.4	Overactive disorder associated with mental retardation and
F04.4	stereotyped movements
F84.5	Asperger's syndrome
F84.8	Other pervasive developmental disorders
F84.9	Unspecified pervasive developmental disorder, current or
#	active state
F88	Other specified delays in development
F89	Unspecified disorder of psychological development
G31.81 ¹	Alpers disease
G80.0	Congenital quadriplegia

G80.1	Congenital diplegia
G80.2	Congenital hemiplegia
G80.3	Athetoid cerebral palsy
G80.4	Ataxic cerebral palsy
G80.8	Other specified infantile cerebral palsy
G80.9	Infantile cerebral palsy, unspecified
M95.2, Q04.0, Q04.1, Q04.2, Q04.3, Q04.4, Q04.5, Q04.6, Q04.8, Q04.9	Other acquired deformity of head, congenital malformations of the brain
P04.3	Alcohol affecting fetus or newborn via placenta or breast milk
Q67.6, Q76.7, Q67.8, Q68.1, Q74.3	Larsen syndrome
Q70.00, Q70.01, Q70.02, Q70.03, Q70.10, Q70.11, Q70.12, Q70.13, Q70.20, Q70.21, Q70.22, Q70.23, Q70.30, Q70.31, Q70.32, Q70.33, Q70.4, Q70.9	Syndactyly
Q85.1	Tuberous Sclerosis
Q86.0, Q86.1	Fetal alcohol syndrome
Q87.1	Congenital malformation syndromes predominantly associate with short stature
Q87.11	Prader-Willi Syndrome
Q87.19	Other congenital malformation syndromes predominantly associated with short stature
Q87.2	Congenital malformation syndromes predominantly involving limbs
Q87.3	Congenital malformation syndromes involving early overgrow
Q87.5	Other congenital malformation syndromes with other skeletal changes
Q87.81	Alport syndrome
Q87.82	Other specified congenital anomalies
Q87.89	Other specified congenital malformation syndromes, not elsewhere classified
Q89.7	Multiple congenital malformations, not elsewhere classified
Q89.8	Other specified congenital malformations
Q90.0	Trisomy 21, nonmosaicism (meiotic nondisjunction)
Q90.1	Trisomy 21, mosaicism (mitotic nondisjunction)
Q90.2	Trisomy 21, translocation
Q90.9	Down syndrome, unspecified (Trisomy 21 NOS)
Q91.0	Trisomy 18, nonmosaicism (meiotic nondisjunction)
Q91.1	Trisomy 18, mosaicism (mitotic nondisjunction)
Q91.2	Trisomy 18, translocation
Q91.3	Edwards' syndrome
Q91.4	Trisomy 13, nonmosaicism (meiotic nondisjunction)
Q91.5	Trisomy 13, mosaicism (mitotic nondisjunction)
Q91.6	Trisomy 13, translocation
Q91.7	Trisomy 13, unspecified Patau's syndrome

	Q92.0	Whole chromosome trisomy, nonmosaicism (meiotic
		nondisjunction)
	Q92.1	Whole chromosome trisomy, mosaicism (mitotic
		nondisjunction)
	Q92.2	Partial trisomy
	Q92.5	Duplications with other complex rearrangements
	Q92.61, Q92.62	Marker chromosomes in abnormal individual
	Q92.7	Triploidy and polyploidy
	Q92.8	Other specified trisomies and partial trisomies of autosomes Other conditions due to autosomal anomalies
	Q92.9	Trisomy and partial trisomy of autosomes, unspecified
	Q93.0	Whole chromosome monosomy, nonmosaicism (meiotic nondisjunction)
	Q93.1	Whole chromosome monosomy, mosaicism (mitotic nondisjunction)
	Q93.2	Chromosome replaced with ring, dicentric or isochromosome
	Q93.3	Deletion of short arm of chromosome 4
	Q93.4	Deletion of short arm of chromosome 5 Cri-du-chat syndrome
	Q93.5	Angelman syndrome Other deletions of part of a chromosome
	Q93.51	Angelman syndrome Other deletions of part of a chromosome
	Q93.59	Deletions with other complex rearrangements Other deletions of part of a chromosome
	Q93.7	Deletions with other complex rearrangements
	Q93.81	Velo-cardio-facial syndrome
	Q93.88	Williams syndrome Other microdeletions
	Q93.89	Other deletions from the autosomes
	Q93.9	Deletion from autosomes, unspecified
	Q95.2	Balanced autosomal rearrangement in abnormal individual
	Q95.3	Balanced sex/autosomal rearrangement in abnormal individual
	Q99.2	Fragile X chromosome
	R41.83	Borderline intellectual functioning
Discharge	270	Disorders of amino-acid transport and metabolism
Diagnosis:	270	Disturbances of amino-acid transport
ICD-9-CM	270.1	Phenylketonuria (PKU)
	270.2	Other disturbances of aromatic amino-acid metabolism
	270.2	Disturbances of branched-chain amino-acid metabolism
	270.4	Disturbances of sulphur-bearing amino-acid metabolism
	270.4	Disturbances of histidine metabolism
	270.5	Distributices of histidite metabolism
		•
	270.7	Other disturbances of straight-chain amino-acid metabolism
	270.8	Other specified disorders of amino-acid metabolism
	270.9	Unspecified disorder of amino-acid metabolism
	271	Disorders of carbohydrate transport and metabolism
	271	Glycogenosis
	271.1	Galactosemia
	271.2	Hereditary fructose intolerance

271.3	Intestinal disaccharidase deficiencies and disaccharide	
271.5	malabsorption	
271.4	Renal glycosuria	
271.8	Other specified disorders of carbohydrate transport and	
	metabolism	
271.9	Unspecified disorder of carbohydrate transport and metabolism	
272.7	Fabry (-Anderson) disease	
	Gaucher disease	
077.0	Niemann-Pick disease	
277.2	Lesch Nyhan Syndrome	
299.11	Childhood disintegrative disorder, residual state	
299.8	Other specified pervasive developmental disorders, current or active state	
299.81	Other specified pervasive developmental disorders, residual state	
299.9	Unspecified pervasive developmental disorder, current or active state	
299.91	Unspecified pervasive developmental disorder, residual state	
315.4	Specific developmental disorder of motor function	
315.5	Mixed development disorder	
315.8	Other specified delays in development	
315.9	Unspecified disorder of psychological development	
317	Mild intellectual disabilities	
318.0	Other specified intellectual disabilities	
318	Moderate intellectual disabilities	
318.1	Severe intellectual disabilities	
318.2	Profound intellectual disabilities	
319	Unspecified intellectual disabilities	
330	Krabbe disease	
	Metachromatic leukodystrophy	
330.1	Neuronal ceroid lipofuscinosis	
330.8	Alpers disease	
	Rett's syndrome	
330.0, 330.1, 330.2, 330.3, 330.9	Cerebral Degenerations Manifest in Childhood	
333.71	Athetoid cerebral palsy	
343.0	Congenital diplegia	
343	Spastic diplegic cerebral palsy	
343.1	Congenital hemiplegia	
343.2	Spastic quadriplegic cerebral palsy	
010.2	Congenital quadriplegia	
343.3	Congenital monoplegia	
343.4	Infantile hemiplegia	
343.8	Other specified infantile cerebral palsy	
343.9	Cerebral palsy, unspecified	
	Infantile cerebral palsy, unspecified	
520	Childhood cerebral X-linked adrenoleukodystrophy	
754.8	Larsen syndrome	
755.1	Syndactyly	
758.0	Chromosomal anomalies	

1	750	Down oundrome upon actived (Tricomy 04 NOO)
	758	Down syndrome, unspecified (Trisomy 21 NOS)
		Trisomy 21, mosaicism (mitotic nondisjunction) Trisomy 21, nonmosaicism (meiotic nondisjunction)
		Trisomy 21, translocation
	758.1	Trisomy 13, mosaicism (mitotic nondisjunction)
		Trisomy 13, nonmosaicism (meiotic nondisjunction)
		Trisomy 13, translocation
		Trisomy 13, unspecified Patau's syndrome
	758.2	Trisomy 18, mosaicism (mitotic nondisjunction)
		Trisomy 18, nonmosaicism (meiotic nondisjunction)
		Trisomy 18, translocation
		Trisomy 18, unspecified
	750.0	Edwards' syndrome
	758.3	Autosomal deletion syndromes
	758.31	Deletion of short arm of chromosome 5
	750.00	Cri-du-chat syndrome
	758.32	Velo-cardio-facial syndrome
	758.33	Williams syndrome
	759.20	Other microdeletions
	758.39	Deletion from autosomes, unspecified Deletion of short arm of chromosome 4
		Deletions with other complex rearrangements
		Other deletions from the autosomes
		Other autosomal deletions
	758.5	Other conditions due to autosomal anomalies
	759.5	Tuberous Sclerosis
	759.7	Multiple congenital malformations, not elsewhere classified
	759.81	Prader-Willi Syndrome
	759.83	Fragile X chromosome
	759.89	Alport syndrome
	100.00	Barth syndrome
		Congenital malformation syndromes involving early overgrowth
		Congenital malformation syndromes predominantly involving
		limbs
		Other congenital malformation syndromes with other skeletal
		changes
		Other specified congenital malformation syndromes, not
		elsewhere classified Other specified congenital malformations
		Smith-Lemli-Opitz syndrome
		Other specified congenital anomalies
	299.0, 299.00, 299.01, 299.90	Autism Spectrum Disorders
	299.1, 299.10	Childhood disintegrative disorder
	299.80, 299.81	Asperger's syndrome
		Other pervasive developmental disorders
	333.71, 343, 343.0, 343.2, 343.9	Cerebral Palsy
	343.1, 343.4	Spastic hemiplegic cerebral palsy
	1855002	Developmental disorder of scholastic skills, unspecified
Discharge		Tuberous Sclerosis
Diagnosis	7199000	
code –	8447006	Other congenital malformation syndromes with other skeletal
SNOMED	10406007	changes Lesch Nyhan Syndrome
1	1040007	Loson Nyhan Oyhulome

16652001	Fabry (-Anderson) disease	
17122004	Deletion of short arm of chromosome 4	
17760001	Trisomy 13, unspecified	
00445004	Patau's syndrome	
20415001	Alpers disease	
23560001	Asperger's syndrome	
31216003	Profound intellectual disabilities	
35919005	Other pervasive developmental disorders Pervasive developmental disorder, unspecified Unspecified pervasive developmental disorder, current or active state	
40700009	Severe intellectual disabilities	
40930008	Congenital hypothyroidism	
42012007	Neuronal ceroid lipofuscinosis	
43929004	Smith-Lemli-Opitz syndrome	
48637007	Congenital malformation syndromes involving early overgrowth	
58193001	Congenital diplegia	
58459009	Niemann-Pick disease	
59033006	Trisomy 18, unspecified Edwards' syndrome	
61152003	Moderate intellectual disabilities	
66091009	Chromosomal anomalies, autosomal deletion syndromes and other congenital anomalies (i.e., Down syndrome, Patau'syndrome, Edwards' syndrome, cri-du-chat syndrome, velo-cardio-facial syndrome, other microdeletions, other autosomal deletions, other conditions due to autosomal anomalies, multiple congenital anomalies, Prader-Willi syndrome, Fragile X syndrome and other specified congenital anomalies)† CMS algorithim for intellectual disabilities and related conditions	
68618008	Rett's syndrome	
70156005	Down syndrome, unspecified (Trisomy 21 NOS)	
70173007	Deletion of short arm of chromosome 5 Cri-du-chat syndrome	
71961003	Other childhood disintegrative disorder	
74345006	Deletions with other complex rearrangements	
75019001	Athetoid cerebral palsy	
76880004	Angelman syndrome	
77287004	Borderline intellectual functioning	
82354003	Other specified congenital malformation syndromes, not elsewhere classified	
86765009	Mild intellectual disabilities	
110359009	Other intellectual disabilities Unspecified intellectual disabilities Unspecified intellectual disabilities	
128188000	Cerebral palsy, unspecified Cerebral palsy, unspecified Other cerebral palsy Congenital monoplegia Infantile cerebral palsy, unspecified Other specified infantile cerebral palsy	

190794006	Gaucher disease
192562009	Other disorders of psychological development
	Unspecified disorder of psychological development
400700005	Other specified delays in development
192782005	Krabbe disease
205615000	Trisomy 21, nonmosaicism (meiotic nondisjunction)
205616004	Trisomy 21, mosaicism (mitotic nondisjunction)
205619006	Trisomy 13, nonmosaicism (meiotic nondisjunction)
205620000	Trisomy 13, mosaicism (mitotic nondisjunction)
205623003	Trisomy 18, nonmosaicism (meiotic nondisjunction)
205624009	Trisomy 18, mosaicism (mitotic nondisjunction)
205627002	Other autosomal deletions
205636003	Whole chromosome monosomy, nonmosaicism (meiotic nondisjunction)
205660004	Partial trisomy
205666005	Duplications with other complex rearrangements
205673000	Balanced autosomal rearrangement in abnormal individual
205674006	Balanced sex/autosomal rearrangement in abnormal individual
205720009	Fragile X chromosome
205788004	Fetal alcohol syndrome
205791004	Newborn affected by maternal use of alcohol
205808005	Congenital malformation syndromes predominantly associated
200000000	with short stature
205812004	Congenital malformation syndromes predominantly involving
	limbs
238028008	Cerebral Degenerations Manifest in Childhood
254264002	Trisomy 21, translocation
254266000	Trisomy 18, translocation
254268004	Trisomy 13, translocation
254269007	Whole chromosome trisomy, nonmosaicism (meiotic
	nondisjunction)
254270008	Whole chromosome trisomy, mosaicism (mitotic
054070000	nondisjunction)
254272000	Triploidy and polyploidy
254274004	Angelman syndrome Deletion from autosomes, unspecified
	Other deletions from the autosomes
	Other deletions of part of a chromosome
	Other deletions of part of a chromosome
268674003	Mixed development disorder
270520003	Whole chromosome monosomy, mosaicism (mitotic nondisjunction)
270521004	Other specified trisomies and partial trisomies of autosomes
	Trisomy and partial trisomy of autosomes, unspecified Other conditions due to autosomal anomalies
274908005	Deletions with other complex rearrangements
276654001	Other specified congenital malformations
278512001	Ataxic cerebral palsy
297231002	Barth syndrome
373413006	Syndactyly

Exclusions	None	None
Complaint Terms		(down) AND (syndrome), cerebral palsy, autism, adaptive neurological modifications
Chief	1313000, 00320001	(development,intellectual) AND (delay, disorder, disability),
	7573000, 68528007	the brain Phenylketonuria (PKU)
	111246005 57148006, 111270009	Other acquired deformity of head, congenital malformations of
	391987005, 254041007, 75511006, 34111000,	Larsen syndrome
	267431006, 276654001	Other specified congenital anomalies
	813921000000104	Spastic hemiplegic cerebral palsy Congenital hemiplegia Infantile hemiplegia
	367041000119108	Childhood cerebral X-linked adrenoleukodystrophy
	1010276004	Chromosome replaced with ring, dicentric or isochromosome
	770414008	Alport syndrome Prader-Willi Syndrome
	767263007	Velo-cardio-facial syndrome
	471282000	Williams syndrome Other microdeletions
	444655009	Marker chromosomes in abnormal individual
	409709004	Chromosomal anomalies
	408856003	Autistic Disorder
	400038003	Multiple congenital malformations, not elsewhere classified
	396338004	Metachromatic leukodystrophy

<u>Plain Language Syntax Description:</u> The Intellectual and Developmental Disability (v1) definition intends to identify emergency department visits by people with intellectual and developmental disabilities. The definition includes diagnosis codes and words related to intellectual and developmental disabilities. Users can combine the Intellectual and Developmental Disabilities 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 intellectual and developmental disabilities. This definition will not capture everyone with intellectual and developmental disabilities, 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, Intellectual and Developmental Disability (v1) Definition

This definition was tested and intended to run on the "CC and DD parsed free text" field in ESSENCE.
This definition was tested and intended to full on the CC and DD parsed nee text field in ESSENCE.
Intellectual and Developmental Disability ICD9
 ^;270;^,or,^;270[0-9];^,or,^;271;^,or,^;271[0-9];^,or,^;2701;^,or,^;2701[0-
9];^,or,^;2727;^,or,^;2727[0-9];^,or,^;2772;^,or,^;2772[0-9];^,or,^;299;^,or,^;299[0-
9];^,or,^;299[0-9][0-9];^,or,^;31[789];^,or,^;31[789][0-9];^,or,^;31[789][0-9];^
9];^,or,^;315[4589];^,or,^;330;^,or,^;330[0-9];^,or,^;33371;^,or,^;343;^,or,^;343[0-
9];^,or,^;343[0-9][0-9];^,or,^;520;^,or,^;520[0-9];^,or,^;520[0-9][0-
9];^,or,^;7548;^,or,^;7548[0-9];^,or,^;7551;^,or,^;7551[0-
9];^,or,^;758;^,or,^;758[01235];^,or,^;758[01235][0-9]^,or,^;7583[1-
9];^,or,^;759[57];^,or,^759[57][0-9];^,or,^;7598[139];^,or,^;7607[17];^
• ICD10
o ^;E03[01]^,or,^;E70^,or,^;E70[01234589]^,or,^;E70[2348][0-9]^,or,^;E70[3][0-9][0-
9]^,or,^;E71^,or,^;E71[012345]^,or,^;E71[1345][0-9]^,or,^;E71[345][0-9][0-
9]^,or,^;E72^,or,^;E72[0123459]^,or,^;E72[01258][0-
9]^,or,^;E74^,or,^;E74[012348]^,or,^;E74[01238][0-9]^,or,^;E748[0-9][0-
9]^,or,^;E75^,or,^;E75[0123456]^,or,^;E75[012][0-9]^,or,^;E752[0-9][0-
9]^,or,^;E76^,or,^;E76[012389]^,or,^;E76[02][0-9]^,or,^;E762[0-9][0-
9]^,or,^;E77^,or,^;E77[0-9]^,or,^;E787[12]^,or,^;E791^,or,^;F7[0-9]^,or,^;F7[0-9][0-
9]^,or,^;F78A^,or,^;F78A[19]^,or,^;F8[489]^,or,^;F84[0-9]^,or,^;G3181^,or,^;G80[0- 9]^,or,^;M952^,or,^;P043^,or,^;Q04[0-
9]^,or,^;Q67[678]^,or,^;Q68[01]^,or,^;Q70[49]^,or,^;Q70[0123][0123]^,or,^;Q743^,or,^;Q
767^,or,^;Q851^,or,^;Q86[01]^,or,^;Q87[1235]^,or,^;Q871[19]^,or,^;Q878[129]^,or,^;Q89
[78]^,or,^;Q90[0129]^,or,^;Q91[0-
7]^,or,^;Q92[0125789]^,or,^;Q926[12]^,or,^;Q93[0123479]^,or,^;Q935[19]^,or,^;Q938[18
9]^,or,^;Q95[23]^,or,^;Q992^,or,^;R4183^
 SNOMED
o ^;1855002;^,or,^;7199000;^,or,^;7573000;^,or,^;8447006;^,or,^;10406007;^,or,^;166520
01;^,or,^;17122004;^,or,^;17760001;^,or,^;20415001;^,or,^;23560001;^,or,^;31216003;^,
or,^;34111000;^,or,^;35919005;^,or,^;40700009;^,or,^;40930008;^,or,^;42012007;^,or,^;
43929004;^,or,^;48637007;^,or,^;57148006;^,or,^;58193001;^,or,^;58459009;^,or,^;5903
3006;^,or,^;61152003;^,or,^;66091009;^,or,^;68528007;^,or,^;68618008;^,or,^;70156005
;^,or,^;70173007;^,or,^;71961003;^,or,^;74345006;^,or,^;75019001;^,or,^;75511006;^,or,
^;76880004;^,or,^;77287004;^,or,^;82354003;^,or,^;86765009;^,or,^;110359009;^,or,^;1
11246005;^,or,^;111270009;^,or,^;128188000;^,or,^;190794006;^,or,^;192562009;^,or,^;
192782005;^,or,^;205615000;^,or,^;205616004;^,or,^;205619006;^,or,^;205620000;^,or,
^;205623003;^,or,^;205624009;^,or,^;205627002;^,or,^;205636003;^,or,^;205660004;^,o
r,^;205666005;^,or,^;205673000;^,or,^;205674006;^,or,^;205720009;^,or,^;205788004;^,
or,^;205791004;^,or,^;205808005;^,or,^;205812004;^,or,^;238028008;^,or,^;254041007;
^,or,^;254264002;^,or,^;254266000;^,or,^;254268004;^,or,^;254269007;^,or,^;25427000

8;^,or,^;254272000;^,or,^;254274004;^,or,^;267431006;^,or,^;268674003;^,or,^;2705200 03;^,or,^;270521004;^,or,^;274908005;^,or,^;276654001;^,or,^;278512001;^,or,^;297231 002;^,or,^;373413006;^,or,^;391987005;^,or,^;396338004;^,or,^;400038003;^,or,^;40885 6003;^,or,^;409709004;^,or,^;444655009;^,or,^;471282000;^,or,^;767263007;^,or,^;7704 14008;^,or,^;1010276004;^,or,^;367041000119108;^,or,^;813921000000104;^ All together ^ ^;270;^,or,^;270[0-9];^,or,^;271;^,or,^;271[0-9];^,or,^;2701;^,or,^;2701[0-9];^,or,^;2727;^,or,^;2727[0-9];^,or,^;2772;^,or,^;2772[0-9];^,or,^;299;^,or,^;299[0-9];^,or,^;299[0-9][0-9];^,or,^;31[789];^,or,^;31[789][0-9];^,or,^;315[4589];^,or,^;330[0-9];^,or,^;520[0-9];^,or,^;520[0-9];^,or,^;520[0-9]];^,or,^;520[0-9]];^,or,^;520[0-9];^,or,^;520[0-9];^,or,^;520[0-9];^,or,^;520[0-9];^,or,^;520[0-9]];^,or,^;520[0-9];^,or,^;520[0-9];^,or,^;520[0-9];^,or,^;520[0-9]];^,or,^;520[0-9]];^,or,^;520[0-9];^,or,^;520[0-9];^,or,^;520[0-9];^,or,^;520[0-9];^,or,^;520[0-9]];^,or,^;520[0-9]];^,or,^;520[0-9];^,or,^;520[0-

9];^,or,^;343[0-9][0-9];^,or,^;520;^,or,^;520[0-9];^,or,^;520[0-9][0-9];^,or,^;7548;^,or,^;7548[0-9];^,or,^;7551;^,or,^;7551[0-9];^,or,^;758;^,or,^;758[01235];^,or,^;758[01235][0-9]^,or,^;7583[1-9];^,or,^;759[57];^,or,^759[57][0-9];^,or,^;7598[139];^,or,^;7607[17];^,or,^;E03[01]^,or,^;E70^,or,^;E70[01234589]^,or,^;E7 0[2348][0-9]^,or,^;E70[3][0-9][0-9]^,or,^;E71^,or,^;E71[012345]^,or,^;E71[1345][0-9]^,or,^;E71[345][0-9][0-9]^,or,^;E72^,or,^;E72[0123459]^,or,^;E72[01258][0-9]^,or,^;E74^,or,^;E74[012348]^,or,^;E74[01238][0-9]^,or,^;E748[0-9][0-9]^,or,^;E75^,or,^;E75[0123456]^,or,^;E75[012][0-9]^,or,^;E752[0-9][0-9]^,or,^;E76^,or,^;E76[012389]^,or,^;E76[02][0-9]^,or,^;E762[0-9][0-9]^,or,^;E77^,or,^;E77[0-9]^,or,^;E787[12]^,or,^;E791^,or,^;F7[0-9]^,or,^;F7[0-9][0-9]^,or,^;F78A^,or,^;F78A[19]^,or,^;F8[489]^,or,^;F84[0-9]^,or,^;G3181^,or,^;G80[0-9]^,or,^:M952^,or,^:P043^,or,^:Q04[0-9]^,or,^;Q67[678]^,or,^;Q68[01]^,or,^;Q70[49]^,or,^;Q70[0123][0123]^,or,^;Q743^,or,^;Q 767^,or,^;Q851^,or,^;Q86[01]^,or,^;Q87[1235]^,or,^;Q871[19]^,or,^;Q878[129]^,or,^;Q89 [78]^,or,^:Q90[0129]^,or,^:Q91[0-7]^,or,^;Q92[0125789]^,or,^;Q926[12]^,or,^;Q93[0123479]^,or,^;Q935[19]^,or,^;Q938[18 9]^,or,^;Q95[23]^,or,^;Q992^,or,^;R4183^,or,^;1855002;^,or,^;7199000;^,or,^;7573000;^, or,^;8447006;^,or,^;10406007;^,or,^;16652001;^,or,^;17122004;^,or,^;17760001;^,or,^;2 0415001;^,or,^;23560001;^,or,^;31216003;^,or,^;34111000;^,or,^;35919005;^,or,^;40700 009;^,or,^;40930008;^,or,^;42012007;^,or,^;43929004;^,or,^;48637007;^,or,^;57148006; ^.or,^;58193001;^.or,^;58459009;^.or,^;59033006;^.or,^:61152003;^.or,^:66091009;^.or, ^;68528007;^,or,^;68618008;^,or,^;70156005;^,or,^;70173007;^,or,^;71961003;^,or,^;74 345006:^.or,^:75019001:^.or,^:75511006:^.or,^:76880004:^.or,^:77287004:^.or,^:823540 03;^,or,^;86765009;^,or,^;110359009;^,or,^;111246005;^,or,^;111270009;^,or,^;1281880 00;^,or,^:190794006;^,or,^:192562009;^,or,^:192782005;^,or,^:205615000;^,or,^:205616 004:^,or,^:205619006:^,or,^:205620000:^,or,^:205623003:^,or,^:205624009:^,or,^:20562 7002;^,or,^;205636003;^,or,^;205660004;^,or,^;205666005;^,or,^;205673000;^,or,^;2056 74006;^,or,^;205720009;^,or,^;205788004;^,or,^;205791004;^,or,^;205808005;^,or,^;205 812004;^,or,^;238028008;^,or,^;254041007;^,or,^;254264002;^,or,^;254266000;^,or,^;25 4268004;^,or,^;254269007;^,or,^;254270008;^,or,^;254272000;^,or,^;254274004;^,or,^;2 67431006;^,or,^;268674003;^,or,^;270520003;^,or,^;270521004;^,or,^;274908005;^,or,^; 276654001:^.or,^:278512001:^.or,^:297231002:^.or,^:373413006:^.or,^:391987005:^.or, ^;396338004;^,or,^;400038003;^,or,^;408856003;^,or,^;409709004;^,or,^;444655009;^,o r,^;471282000;^,or,^;767263007;^,or,^;770414008;^,or,^;1010276004;^,or,^;3670410001 19108;^,or,^;813921000000104;^,or,(,(,^development^,or,^intellectual^,),AND,(,^delay^, or,^disorder^,or,^disability^,),),or,(,(,^down^,),AND,(,^syndrome^,),),or,^cerebral palsy^,or,^autism^,or,^adaptive neurological modifications^

<u>Appendix</u>

<u>Definition Evolution During Development</u>: Intellectual and Developmental Disability (v1)

Iteration 1: The first iteration of the definition included domains of Hearing, Vision, Mobility, Intellectual and Developmental Disability, and Cognition and Central Nervous System Disorders. This first definition was presented to the scientific panel. • 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:
 Intellectual and Developmental Disability Included deformity of the skull and congenital malformations of the brain into Intellectual and Developmental Disability following Larson et. al. 2001
 Added congenital hypothyroidism to Intellectual and Developmental Disability following Larson et. al. 2001
 Moved ADHD and hyperkinetic syndromes from mental health additions to the Intellectual and Developmental Disability domain
Iteration 3: The third iteration was provided to the scientific panel for feedback and edits. The following changes were made:
 Intellectual and Developmental Disability and Specific Developmental or Learning Renamed Learning domain to "Specific Developmental or Learning" Moved ADHD, conduct disorders and hyperkinetic syndromes from Intellectual and Developmental Disability to Specific Developmental or Learning. These codes include all codes under 312, 314 (ICD9), F63, F90, F91 (ICD10), and 66347000, 406506008, 430909002 (SNOMED).
Iteration 4: Following the third scientific panel, CDC pilot-tested the definition at the national level. The following changes were made:
General O 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:
 Intellectual and Developmental Disability Cleaned up ICD-9, ICD-10, and SNOMED of duplicate codes in Excel sheet. Deleted codes for scientific panel's final decision to move ADHD and Conduct disorders out of this domain.
Iteration 6: Prior to the fourth scientific panel, the definition development team met with members of a project team at the Office of the Assistance Secretary of Planning and Evaluation (ASPE) regarding an ongoing ASPE project to develop a definition for Intellectual and Developmental Disability. The definition development team conducted a crosswalk of the two definitions resulting in the following changes:
Intellectual and Developmental Disability and Specific Developmental and Learning

0	Developmental disorder of scholastic skills (F81.9, V40.0) were moved from
	Intellectual and Developmental Disability to the Specific Development or Learning

- Pervasive developmental disorder was moved from the Specific Development or Learning domain to Intellectual and Developmental Disability
- The series of codes for Lambert-Eaton syndrome (G70) was added to Intellectual and Developmental Disability
- 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.

- Intellectual and Developmental Disability Suggested to move Lambert-Eaton syndrome (e.g., G70.00, G70.01, G70.1, G70.2, G70.80, G70.81, G70.89, G70.9) to chronic domain as this condition is generally not considered developmental and is often associated with small cell lung cancer. In a subset of cases, it develops following another autoimmune disease. Examining the code list within HCUP data, demographics look more like the population without intellectual and developmental disabilities; these codes are prevalent in hospitalization data and often captures myasthenia gravis (autoimmune).
- Suggested to remove specific developmental disorder of motor function (e.g., F82) as it is conceptually clearer to keep under Specific Developmental domain and not in Intellectual and Developmental Disability as well.

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

- Intellectual and Developmental Disability Moved Lambert-Eaton syndrome to chronic domain
- Removed specific developmental disorder of motor function, F82 as it is covered under Specific Developmental domain. Prior to removal, CDC consulted with two emergency physicians to determine how F82 code is typically used; they advised it should be okay to remove from Intellectual and Developmental Disability as this code is unlikely to be used alone for more comprehensive disabilities that would be included under Intellectual and Developmental Disability.

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