



OFFICE OF THE SECRETARY
PATIENT-CENTERED OUTCOMES
RESEARCH TRUST FUND

PROJECT REPORT

FINAL REPORT

Advancing an Operational Definition of Intellectual and Developmental Disabilities for Use in Research

Prepared for
The Office of the Assistant Secretary for Planning and Evaluation
at the U.S. Department of Health and Human Services

by
NORC at the University of Chicago

MARCH 2026

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This report was funded by the Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) under Contract Number HHSP233201500048II of the HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE). The work was carried out by NORC at the University of Chicago and ASPE staff. The authors are solely responsible for this document's contents, findings, and conclusions, which do not necessarily represent the views of HHS, ASPE, or NORC. Readers should not interpret any statement in this product as an official position of ASPE or HHS.

Suggested Citation: Srinivasan M, Zott C, Hu W, Brown D, Byrne M, Reichard A, Plourde E, Okafor M, and Dullabh P. Advancing an Operational Definition of Intellectual and Developmental Disabilities for Use in Research. Washington, D.C.: Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. March 2026.

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ACKNOWLEDGEMENTS

The authors would like to acknowledge ASPE and ACL staff who provided feedback on previous versions of this report, including CAPT Jennifer Wiltz, MD, MPH (ASPE), Marcos Trevino, MPH (ASPE), Helen Lamont, PhD (ASPE), and Jennifer Johnson, Ed.D. (ACL).

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Executive Summary

Background. Accurately estimating the prevalence of intellectual and developmental disabilities (ID/DD) in the United States remains a challenge, with reported rates varying widely (3%-17%) based on the definitions and data sources used. Administrative data, especially from Medicare and Medicaid claims, due to their broad population coverage and longitudinal structure, can be a valuable resource for identifying and monitoring the health of individuals with many conditions, including ID/DD. However, current tools like the Centers for Medicare & Medicaid Services' Chronic Conditions Data Warehouse (CCW) condition flags for intellectual disabilities, autism spectrum disorders, and other developmental disabilities exclude many potentially relevant diagnoses, leading to substantial variation across federal and nonfederal research in International Classification of Diseases (ICD) diagnosis codes included in claims-based ID/DD definitions.

Objectives. In this brief, we present findings from a descriptive analysis of Medicare and Medicaid administrative data and discussions with a multidisciplinary technical expert panel (TEP) toward informing a future update to the CCW condition flags for ID/DD.

Methods. We first constructed a baseline ID/DD definition comprising six conditions that built on ICD-10 codes used in the 2024 CCW condition flags, supplemented by TEP input. TEP members were convened at a two-hour virtual meeting in November 2024 and asynchronously before and after the meeting. With the aid of prior research and TEP input, we also identified eight additional conditions and associated ICD-10 codes for consideration to expand the baseline definition. We then analyzed Medicare and Medicaid claims and encounter data from 2021–2022 for beneficiaries aged 2 years and older, continuously enrolled in either program, and residing in the United States (U.S.) to estimate (1) the prevalence of ID/DD in administrative data using the baseline definition, (2) the prevalence of the eight other conditions, and (3) the co-occurrence of the additional eight conditions with the baseline ID/DD definition. We also convened a multidisciplinary TEP, including clinicians. TEP members also offered important operational considerations for implementing such an expansion.

Results. Among the 125 million eligible Medicare and Medicaid beneficiaries aged 2 years and older, 2.9% (or approximately 3.6 million people) had at least one ID/DD diagnosis based on ICD-10 codes in the baseline definition. Fewer beneficiaries had an ID-only diagnosis (0.8%) than a DD-only diagnosis (1.7%), and a smaller subset (0.4%) of beneficiaries had a diagnosis of both ID and DD. The share of beneficiaries with an ID/DD diagnosis declined with age, from 6.4% among the population aged 2-18 years to 0.5% among the population aged 65 years and older. This decline may be due largely to a reduction in DD diagnoses, likely influenced by use of care, service eligibility, and diagnostic practices across the lifespan, as well as shorter life expectancy for some people with DD. Among the eight additional conditions not included in the baseline definition, attention-deficit/hyperactivity disorder (ADHD) had the highest overall prevalence across all age groups at 4.1%, particularly among children and adolescents (9.4%). Other nervous system disorders followed at 3.8% overall, which were most common in older adults (8.1%). Speech and language disorders had the third highest overall prevalence (2.1%), with a concentration among the 2-18 age group (7.5%). The remaining five conditions—learning disabilities, spina bifida, cerebral palsy, other chromosomal abnormalities, and other congenital anomalies—had overall prevalence rates below 0.5%. Co-occurrence analysis of the eight additional conditions with the baseline ID/DD definition revealed that individuals with cerebral palsy were most

likely to also have an ID/DD diagnosis (53.2%), followed by those with other chromosomal abnormalities (47.9%) and speech and language disorders (37.6%). In contrast, ADHD and other nervous system disorders—despite their relatively high prevalence in administrative data—had substantially lower rates of co-occurrence with baseline ID/DD conditions (16.5% and 3.0%, respectively). Co-occurrence rates with baseline ID/DD conditions tended to decline with age for most other conditions, but some, such as learning disabilities and speech and language disorders, had their highest co-occurrence rates in the adult age group (19–64). Among children and adolescents, co-occurrence rates with baseline ID/DD conditions exceeded 20% for all eight additional conditions, with particularly high overlap for chromosomal abnormalities (72.0%), cerebral palsy (65.1%), and spina bifida (50.9%).

Conclusion. The lack of some relevant diagnoses in the CCW ID and DD condition flags, coupled with definitional inconsistencies in research, reduce the generalizability and comparability of research findings for individuals with ID/DD, potentially impeding translation of research into evidence-based policies and care delivery practices for this important population. This exploratory analysis highlights the potential for substantial variation in the size of the ID/DD population depending on which conditions are included in a future expansion of existing CCW condition flags. Our analysis revealed that several other conditions—such as ADHD, speech and language disorders, and cerebral palsy—are prevalent in claims data and often co-occur with ID/DD, particularly among children and adolescents. However, the extent of co-occurrence varied widely across conditions and age groups and may be influenced by diagnostic and billing practices, service eligibility, and lifespan factors. While this analysis offers an important foundation, it is exploratory in nature. Further work is needed to finalize the conditions for use in an expansion of the baseline ID/DD definition, whether they are the eight additional conditions used in this brief or include other conditions.

1. Background

Accurately estimating the prevalence of intellectual and developmental disabilities (ID/DD) in the United States (U.S.) remains a challenge, with reported rates ranging from 3% to 17%, depending on the definitions and data sources used.¹ Although the exact size of the ID/DD population is unknown, individuals with ID/DD likely represent a substantial portion of the U.S. population and often experience complex and intersecting health, behavioral, and social support needs. Despite experiencing higher rates of co-occurring mental and physical health conditions,² people with ID/DD are less likely to receive appropriate health care and preventive services compared to the general population.^{3,4}

Administrative claims and encounter data, due to their broad population coverage and longitudinal structure, can be a valuable resource for identifying and monitoring the health of individuals with many different conditions, including ID/DD. Administrative claims data are billing records submitted by health care providers to insurers in fee-for-service arrangements such as Original Medicare, while encounter data are submitted by managed care plans to document services provided to beneficiaries under capitated payment arrangements or through bundling of services. People with ID/DD predominantly use Medicare and Medicaid programs due to their disability status and related support needs.⁵ Some receive Medicare through disability-related eligibility pathways⁵, while others receive Medicaid coverage for long-term supports and community-based care.⁶ Many are dually eligible for both Medicare and Medicaid⁵, and some choose Medicare Advantage plans as an alternative way to receive Medicare benefits, including through dual-eligible special needs plans.⁷ Although varying eligibility criteria mean that not all individuals with ID/DD are captured within these programs—and therefore within these data sources—administrative claims and encounter data remain a valuable resource to understanding their health status and service utilization.

The Centers for Medicare & Medicaid Services' (CMS) Chronic Conditions Data Warehouse (CCW)—which provides condition flags based on International Classification of Diseases (ICD) diagnosis codes for ID, autism spectrum disorders, and other specific DD—is often used by researchers to define the ID/DD population in claims.⁸ While the CCW flags offer a standardized approach in theory, in practice they do not comprehensively identify ID and DD conditions. Several conditions relevant to ID/DD research—such as cerebral palsy, spina bifida, and learning disabilities—are included in researchers' code lists but are absent from the CCW definitions. This gap has led to substantial differences across federal and nonfederal research in the set of ICD codes included in claims-based definitions of the ID/DD population, as described in a report published in 2023 by the U.S. Department of Health and Human Services Assistant Secretary for Planning and Evaluation (ASPE).⁹ Definitional inconsistencies make it challenging to generalize and compare research findings across studies. A more comprehensive and standardized claims-based definition could improve consistency across research on the population with ID/DD.

In this brief, we present findings from an exploratory analysis of Medicare and Medicaid administrative data and discussions with ID/DD experts toward informing a future update to the CCW condition flags for ID/DD. We describe the prevalence of ID/DD in administrative data based on a “baseline” definition developed from the CCW condition flags. We then examine the prevalence of various other conditions that have been used by researchers that might be important to consider for a future update or expansion of the baseline ID/DD definition. Importantly, this work does not intend for updated CCW condition flags to be used uniformly across all studies. Rather, we envision that updated CCW flags will

serve as a foundation for a more comprehensive and standardized definition for researchers to consider and adapt based on specific analytic goals and/or evolving clinical knowledge. This will promote greater consistency in how ID/DD are identified in health services research while acknowledging important differences in study objectives.

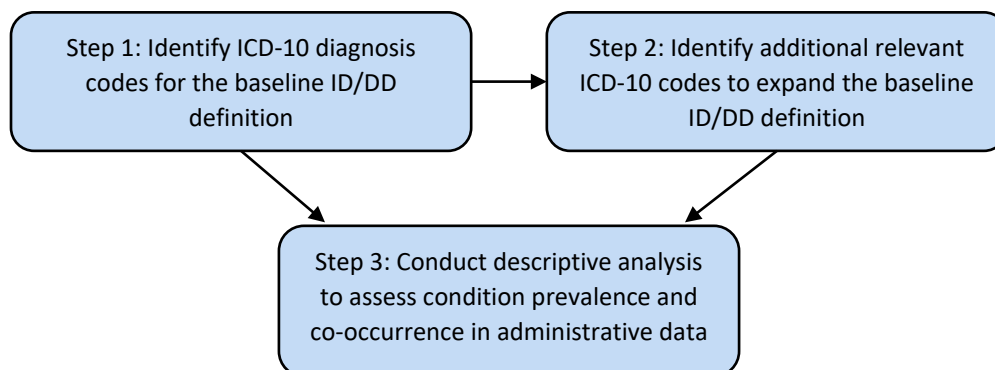
This brief aims to address the following questions:

1. What is the prevalence of ID/DD in administrative data based on a “baseline” definition developed from the CCW condition flags?
 - What is the prevalence of the individual conditions within the baseline ID/DD definition?
2. What are some other conditions not included in the baseline ID/DD definition, but that may be relevant to consider for expanding the ID/DD definition in the future?
 - What is the prevalence of these other conditions in administrative data, and how do they co-occur with the baseline ID/DD definition?

2. Methods

Our methods consisted of three steps to determine relevant ICD-10 codes to be included in the analysis and examine the prevalence of ID/DD conditions in administrative data, outlined in Figure 1.

Figure 1: Methods for Assessing the Prevalence of ID/DD Conditions in Medicare and Medicaid Administrative Data



We also convened a multidisciplinary technical expert panel (TEP) at a two-hour virtual meeting in November 2024 and asynchronously before and after the meeting. The TEP included 21 members, such as clinicians, researchers, federal experts, and people with lived experience of ID/DD. Through their engagement, they provided feedback on additional conditions to consider for an expansion of the baseline ID/DD definition and offered important operational considerations for implementing such an expansion.

Identify ICD-10 Diagnosis Codes for the Baseline ID/DD Definition

Given the widespread use of the CCW condition flags in federal research, we developed a baseline definition of ID/DD that builds on these flags. Specifically, we began with a list of ICD-10 diagnosis codes included in the 2024 CCW condition flags to identify individuals with ID (Intellectual Disabilities flag) and DD (Autism Spectrum Disorders flag and Other Developmental Delays flag).¹⁰ Due to their high association with ID/DD, we added two ICD-10 codes to this list: Q93.82 (Williams syndrome) to the ID

category and F84.2 (Rett's syndrome) to the DD category. We mapped the baseline ICD-10 codes to six condition categories identified in the 2023 ASPE report: intellectual disabilities, congenital malformations of the nervous system, other congenital malformations and chromosomal anomalies, down syndrome, fetal alcohol syndrome, and pervasive and specific developmental disorders.⁶ A full list of codes included in the baseline ID/DD definition is in Appendix A.

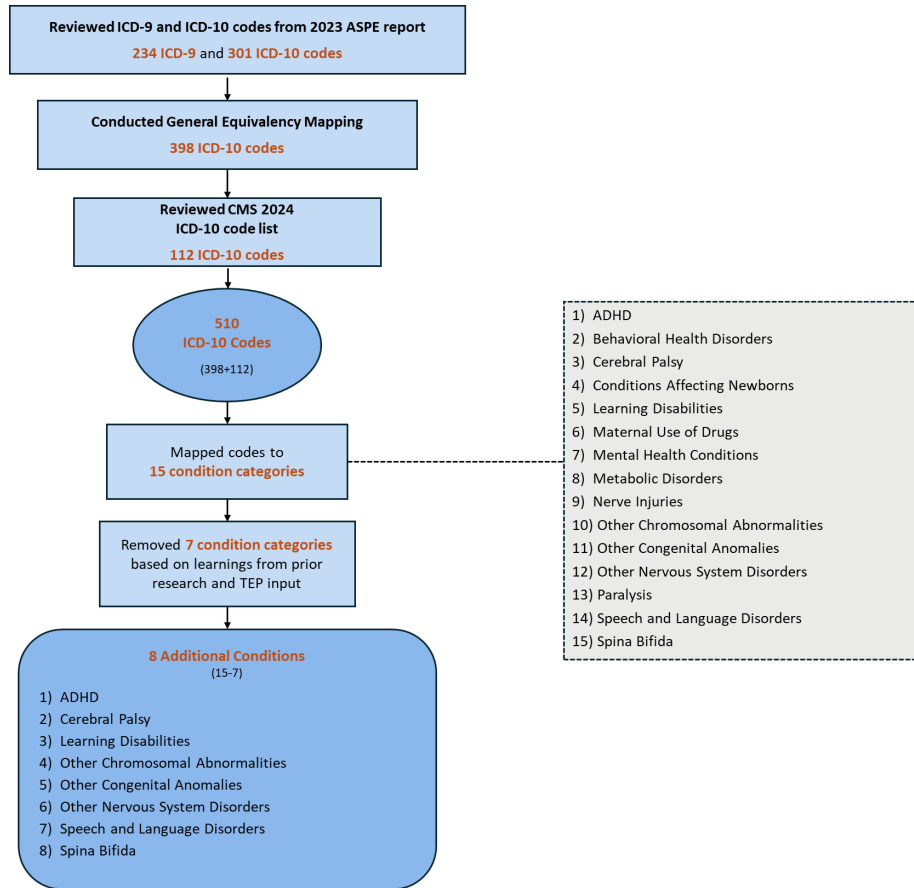
Identify Additional Relevant ICD-10 Codes to Expand the Baseline ID/DD Definition

Figure 2 illustrates the process used to identify eight additional conditions for potential inclusion in future expansion of the baseline ID/DD definition. This process began with creating a list of ICD-10 codes (outside of those in the baseline definition) as follows:

1. First, we reviewed the 234 ICD-9 and 301 ICD-10 codes from the 2023 ASPE report⁶ and conducted general equivalency mapping to create a list of 398 ICD-10 codes that have been used in varying ways by researchers to define the ID/DD population in claims.
2. Second, we reviewed CMS' publicly available 2024 ICD-10 code list to identify 112 additional valid subcodes not explicitly listed in the ASPE report but related to included parent codes. For example, while E83.0 (Disorders of copper metabolism) is a valid code, it is not reimbursable and therefore rarely appears in claims data. However, its reimbursable subcodes (E83.00, E83.01, and E83.09) were added to our list.

We mapped the resulting 510 codes to their relevant CCW classification and/or Agency for Healthcare Research and Quality Clinical Classification Software Refined (CCSR) diagnosis category to group the codes into broader conditions. This process resulted in an initial list of 15 conditions as shown in **Figure 2**. Based on prior research and TEP input, the list was narrowed to eight conditions for inclusion in an analysis of claims and encounter data. These conditions were selected due to their frequent inclusion in definitions reviewed in the 2023 ASPE report and/or their relevance to ongoing discussions about which conditions most appropriately belong in definitions of ID/DD. A full list of ICD-10 codes associated with each of the eight additional conditions selected for the analysis is in Appendix B1, and the ICD-10 codes from the subset of the remaining seven conditions that were not selected are in Appendix B2.

Figure 2: Process for Identifying Additional Conditions for a Potential Expansion of the Baseline ID/DD Definition



Conduct Descriptive Analysis to Assess Condition Prevalence and Co-Occurrence in Administrative Data

After determining the above sets of ICD-10 codes and conditions for the baseline definition and its potential enhancement, we explored their prevalence in Medicare fee-for-service (FFS) claims, Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF) Research Identifiable Files (RIF), and Medicare Advantage encounter data. **The eligible population** included institutionalized and non-institutionalized beneficiaries who were aged 2 years and older by the end of calendar year 2022 who resided in any of the 50 U.S. states or the District of Columbia. Individuals were required to be alive at the beginning of calendar year 2022 and remained continuously enrolled in Medicare or Medicaid in 2021 and 2022 or until death. A unique CCW person-level identifier was used to link CCW data sources across states and payers (Medicare FFS, Medicare Advantage [MA], and Medicaid). Medicare beneficiaries (including those dually-eligible for Medicaid and Medicare) were required to have continuous enrollment in both Part A and Part B if they were in “original” FFS Medicare or MA. Beneficiaries enrolled in Medicaid were required to have continuous enrollment in Medicaid, Children's Health Insurance Program (CHIP), or the Medicaid expansion of CHIP. **Beneficiaries were identified as having ID, DD, or another condition of interest** if they had at least one record in Medicare FFS claims, TAF RIFs, and MA encounter data during the measurement period (2021-2022) that included a relevant ICD-10 diagnosis code from the lists of ICD-10 codes described previously.

We conducted three analyses: (1) estimation of the ID/DD population size and the prevalence of each condition included in the baseline definition, both overall and by three age groups (2-18, 19-64, and 65+); (2) estimation of the prevalence of the eight additional conditions determined to be relevant for an expanded ID/DD definition, also stratified by the three age groups; and (3) analysis of co-occurrence between the baseline ID/DD definition and these additional conditions to assess how frequently they co-occur, overall and by the three age groups. To assess co-occurrence, beneficiaries were required to have at least one record in MA encounter data, Medicare FFS claims, and TAF RIFs with an ID or DD diagnosis (as per the baseline definition) *and* at least one record in MA encounter data, Medicare FFS claims, and TAF RIFs with a diagnosis for the co-occurring condition of interest during the same measurement period.

3. Findings from Administrative Data Analysis

Below we detail findings for each question guiding our analysis.

Question #1: Prevalence of ID/DD Based on the Baseline Definition

The total eligible population included slightly more than 125 million beneficiaries aged 2 years and older continuously enrolled during 2021-2022 as Medicaid-only, dual-eligible, or Medicare-only (FFS and MA) beneficiaries. Of this eligible population, we computed the number and share of beneficiaries in four subpopulations: all individuals with ID and/or DD (hereafter, ID/DD), individuals with ID only, individuals with DD only, and individuals with both ID and DD. We report prevalence in two ways: (1) as a percentage of the total eligible population in the sample and (2) as a percentage of the total eligible population with ID/DD. As seen in **Table 1**, of the total eligible population in the sample, 2.9% (3.6 million beneficiaries) had an ID/DD diagnosis based on the list of ICD-10 codes in the baseline definition.[†] Fewer beneficiaries had an ID-only diagnosis (0.8%) than a DD-only diagnosis (1.7%), and a small subset (0.4%) of beneficiaries had a diagnosis of both ID and DD.

The share of beneficiaries with an ID/DD diagnosis declined with age, from 6.4% among the population aged 2-18 years to 0.5% among the population aged 65 years and older (**Table 1**). This trend may be driven largely by a decline in DD diagnoses with age, which is likely influenced by service eligibility, use, and diagnostic practices across the lifespan. For example, DD diagnoses are often established in childhood when developmental screening is more routine,^{11,12} and the conditions may later resolve or be reclassified.¹³ Additionally, life expectancy may be shorter for some people with DD,¹⁴ and individuals enrolled in Medicaid as children do not always retain eligibility for public insurance when they are reevaluated as adults.¹⁵

[†] The CCW ID and DD flags are based on a sample of Medicaid beneficiaries who have at least one inpatient claim or encounter or at least two other (long term care, outpatient, or professional) medical claims or encounters of any service type. Beneficiaries with only one non-inpatient medical claim or encounter in the measurement period were excluded from the CCW flags for ID/DD. However, we included such beneficiaries in the sample because 57% had at least one claim or encounter for one of the eight additional conditions. To assess the impact of this inclusion, we conducted a sensitivity analysis excluding them, which reduced the ID/DD prevalence from 2.9% to 2.2%.

Table 1: Prevalence of the Baseline Definition of ID/DD in 2021-2022, Overall and by Age Group

Age Group	Denominator	ID only	DD only	ID and DD	ID and/or DD
Overall	Total Number of Beneficiaries	1,022,704	2,086,109	517,122	3,625,935
	% of Total Eligible Population (n=123,239,877)	0.8%	1.7%	0.4%	2.9%
	% of Total Eligible Population with ID and/or DD (n=3,625,935)	28.2%	57.5%	14.3%	-
2-18 years	Total Number of Beneficiaries	154,951	1,674,287	197,312	2,026,550
	% of Total Eligible Population (n=31,732,553)	0.5%	5.3%	0.6%	6.4%
	% of Total Eligible Population with ID and/or DD (n=2,026,550)	7.7%	82.6%	9.7%	-
19-64 years	Total Number of Beneficiaries	705,466	377,115	291,694	1,374,275
	% of Total Eligible Population (n=42,183,314)	1.7%	0.9%	0.7%	3.3%
	% of Total Eligible Population with ID and/or DD (n=1,374,275)	51.3%	27.4%	21.2%	-
65+ years	Total Number of Beneficiaries	162,287	34,707	28,116	225,110
	% of Total Eligible Population (n=49,324,010)	0.3%	0.1%	0.1%	0.5%
	% of Total Eligible Population with ID and/or DD (n=225,110)	72.1%	15.4%	12.5%	-

Table 2 shows the prevalence of each of the six conditions included in the baseline definition of ID/DD used for our analysis, based on administrative data. Pervasive and specific developmental disorders had the highest overall prevalence (2.1%) among the total eligible population and was by far the most common condition among the subset of the eligible population with ID/DD (71.3%). Intellectual disabilities followed with an overall prevalence among the total eligible population of 1.0% and of 34.2% among the population with ID/DD. The other four conditions (congenital malformations of the nervous system, other congenital malformations and chromosomal anomalies, down syndrome, and fetal alcohol syndrome) each represented less than 1% of the total eligible population and less than 5% of the population with ID/DD.

Table 2: Prevalence of the Six Conditions Included in the Baseline Definition of ID/DD in 2021-2022, Overall and by Age Category

ID/DD Condition	Prevalence Type	Overall		Children (2-18 years)		Adults (19-64 years)		Older Adults (65+ years)	
		N	%	N	%	N	%	N	%
Intellectual Disabilities									
Intellectual Disabilities	Total Eligible Population	1,239,360	1.0	233,291	0.7	858,552	2.0	147,517	0.3
	Population with ID/DD		34.2		11.5		62.5		65.5
Congenital Malformations of the Nervous System	Total Eligible Population	72,357	0.1	34,409	0.1	20,897	0.1	17,051	0.3
	Population with ID/DD		2.0		1.7		1.5		7.6
Other Congenital Malformations and Chromosomal Anomalies	Total Eligible Population	114,011	0.1	54,531	0.2	44,072	0.1	15,408	0.0
	Population with ID/DD		3.14		2.7		3.2		6.8
Down Syndrome	Total Eligible Population	173,113	0.1	58,014	0.2	109,674	0.3	5,425	0.0
	Population with ID/DD		4.8		2.9		8.0		2.4
Fetal Alcohol Syndrome	Total Eligible Population	21,481	0.0	11,038	0.0	10,095	0.0	348	0.0
	Population with ID/DD		0.6		0.5		0.7		0.2
Developmental Disabilities									
Pervasive and Specific Developmental Disorders	Total Eligible Population	2,583,464	2.1	1,871,549	5.9	650,290	1.5	61,625	0.1
	Population with ID/DD		71.3		92.4		47.3		27.4

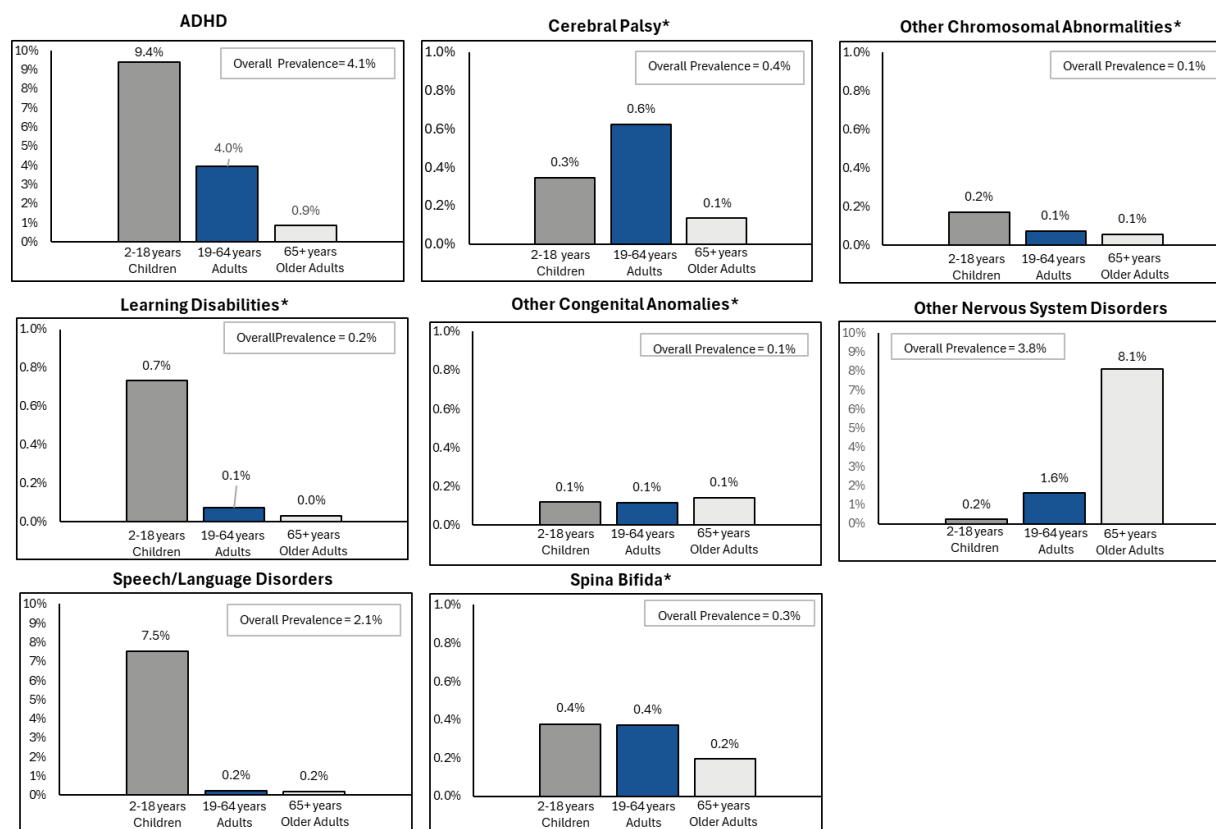
N = the total number of beneficiaries with the specific ID or DD condition; % = the prevalence of the population among either the total eligible population or the population ID and/or DD, as indicated. Percentages of 0.0 indicate very small percentage (i.e., not true zeroes).

Question #2: Prevalence of Additional Conditions and their Co-Occurrence with the Baseline Definition

Figure 3 shows the prevalence of each of the eight additional conditions, based on administrative data, as a percentage of the total eligible population in the sample. These conditions were identified as important to consider in a future expansion of the baseline ID/DD definition. Prevalence is shown overall and stratified by the three age groups. Again there was substantial variation in the prevalence of the eight additional conditions by age group. Attention-deficit/hyperactivity disorder (ADHD) had the

highest overall prevalence (4.1%), particularly among children and adolescents aged 2–18 years (9.4%), compared to adults aged 19–64 years (4.0%) and older adults aged 65 years and older (0.9%). Individuals with other nervous system disorders followed at 3.8%, driven primarily by adults aged 65 and over (8.1%). Speech and language disorders had the third-highest overall prevalence (2.1%), with a concentration among the 2-18 age group (7.5%). All other conditions had lower prevalence overall (<0.5%) and within each age group (<1.0%), with other chromosomal abnormalities having the lowest overall prevalence (0.1%).

Figure 3: Percent of the Eligible Population with at Least One of the Eight Additional Conditions in 2021-2022, Overall and by Age Category



*The scale of each graph has been adjusted for readability; as a result, bar heights may not be directly comparable across graphs.

Table 3 shows the co-occurrence of the baseline definition of ID/DD with each of the eight additional conditions that could be added to the baseline. Among individuals with the eight additional conditions, those with a diagnosis of cerebral palsy had the highest likelihood of co-occurrence with the baseline ID/DD definition (53.2%), followed by those with other chromosomal abnormalities (47.9%) and speech and language disorders (37.6%). In contrast, ADHD and other nervous system disorders—despite their relatively high prevalence—had substantially lower rates of co-occurrence with baseline ID/DD conditions (16.5% and 3.0%, respectively).

There was notable variation in the co-occurrence of the eight additional conditions with baseline ID/DD conditions across age groups. For most of the eight additional conditions, the proportion of individuals

with a co-occurring baseline ID/DD condition declined with age. However, learning disabilities and speech and language disorders showed a different pattern, with the highest rates of co-occurrence with baseline ID/DD conditions observed among adults aged 19-64 years. Among children and adolescents aged 2-18 years, co-occurrence with baseline ID/DD conditions was greater than 20% for all conditions, with particularly high rates among individuals with chromosomal abnormalities (72.0%), cerebral palsy (65.1%), and spina bifida (50.9%). While co-occurrence with baseline ID/DD conditions was generally low among adults aged 65 and older compared to the other age groups, cerebral palsy remained an exception, with a relatively high co-occurrence rate of 28.4%. More detailed information about co-occurrence of each of the eight additional conditions with ID versus DD is in **Appendix C**.

Table 3: Number of Beneficiaries (%) by Age Group with An Additional Condition Co-Occurring with the Baseline Definition of ID/DD in 2021-2022, Overall and by Age Category

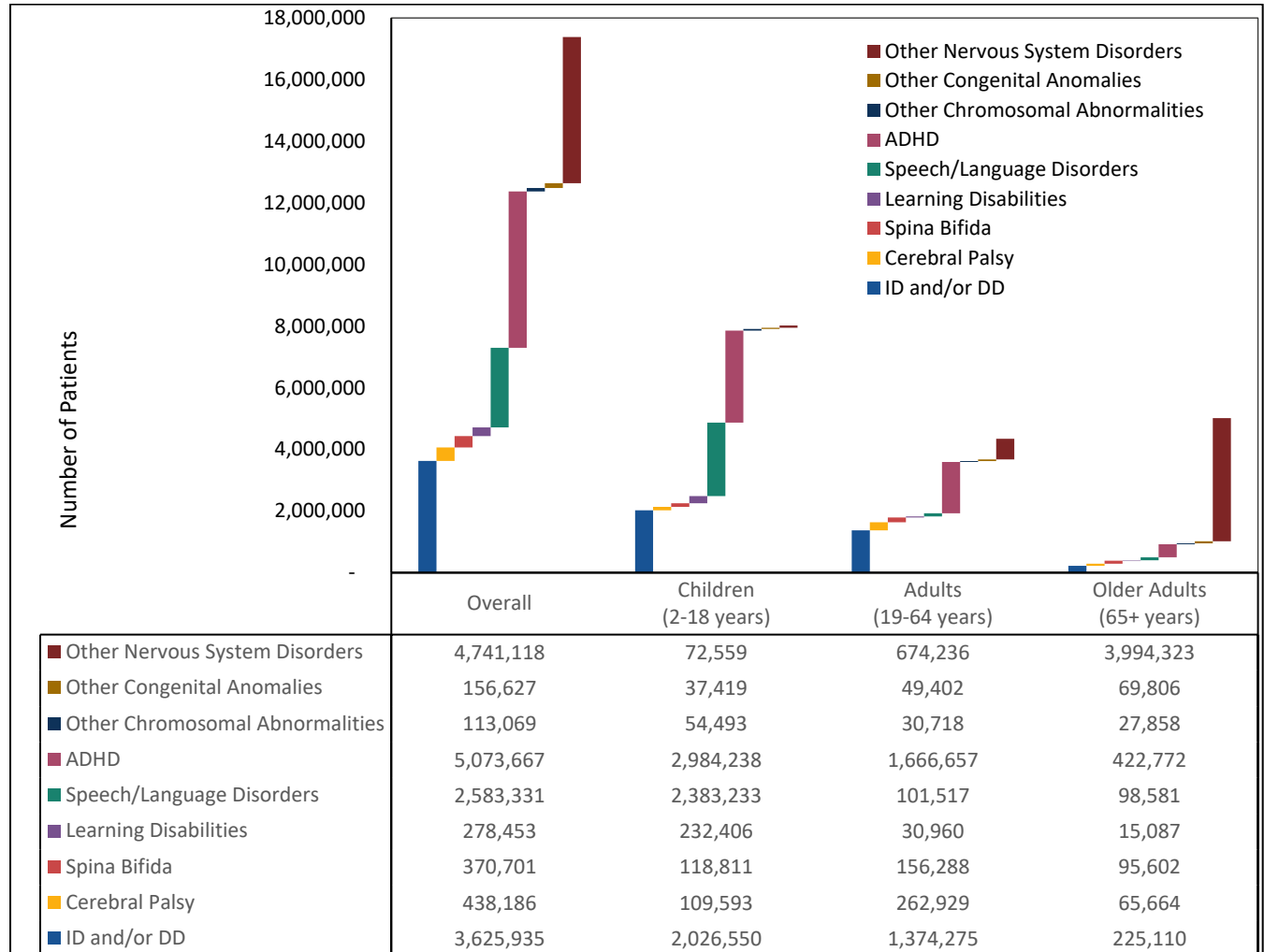
Other Condition	Overall	Children (2-18 years)	Adults (19-64 years)	Older Adults (65+ years)
ADHD	5,073,667 (16.5%)	2,984,238 (20.3%)	1,666,657 (13.2%)	422,772 (2.5%)
Cerebral Palsy	438,186 (53.2%)	109,593 (65.1%)	262,929 (54.4%)	65,664 (28.4%)
Chromosomal Abnormalities	113,069 (47.9%)	54,493 (72.0%)	30,718 (42.7%)	27,858 (6.4%)
Learning Disabilities	278,453 (33.3%)	232,406 (33.1%)	30,960 (44.9%)	15,087 (12.5%)
Other Congenital Anomalies	156,627 (16.0%)	37,419 (31.1%)	49,402 (19.7%)	69,806 (5.3%)
Other Nervous System Disorders	4,741,118 (3.0%)	72,559 (43.5%)	674,236 (10.6%)	3,994,323 (1.0%)
Speech/Language Disorders	2,583,331 (37.6%)	2,383,233 (38.1%)	101,517 (57.2%)	98,581 (5.0%)
Spina Bifida	370,701 (28.3%)	118,811 (50.9%)	156,288 (26.1%)	95,602 (3.7%)

Figure 4 shows the number of beneficiaries who would be included in the ID/DD population if each of the eight additional conditions were added individually to the baseline definition. The values in the graph are not mutually exclusive: each bar represents the impact of adding one condition on its own, without removing individuals who may also qualify under other conditions shown. For example, a person with both a learning disability and spina bifida would be counted in both bars. As a result, the cumulative total from the stepwise bars should not be interpreted as the total ID/DD population if all of the eight additional conditions were included; the actual number would be lower due to co-occurring cases.

Adding ADHD to the definition would augment the baseline ID/DD population size by the most—over 5 million individuals added across all age groups, including nearly 3 million children and adolescents aged 2–18 years. Inclusion of other nervous system disorders would also add a substantial number of individuals to the baseline ID/DD population (approximately 4.7 million), with the majority (nearly 4 million) in the 65 and older age group. Inclusion of speech and language disorders would result in the addition of approximately 2.6 million individuals to the baseline ID/DD population, primarily in the 2-18

age group (2.4 million). In contrast, inclusion of each of the remaining conditions would result in fewer than 500,000 additional people to the baseline ID/DD population.

Figure 4: Co-Occurrence of the Baseline ID/DD Population among Beneficiaries with Eight Additional Conditions of Interest in 2021-2022, Overall and by Age Category



4. Discussion

This brief presents findings from an analysis of Medicare and Medicaid administrative data and discussions with ID/DD experts to inform development of a potential future claims-based ID/DD population definition. The aim was to develop a foundational definition that researchers could consider and adapt based on specific analytic goals and evolving clinical knowledge, while also promoting greater consistency in how ID/DD is identified in health services research — all while acknowledging important differences in study objectives. This work is not intended to impose a national standard or a definition that is applied identically across studies of the population with ID/DD.

Among the total eligible Medicaid and Medicare populations of about 125 million beneficiaries aged 2 years and older, 2.9% (3.6 million beneficiaries) had an ID/DD diagnosis. Fewer beneficiaries had an ID-only diagnosis (0.8%) than a DD-only diagnosis (1.7%), and a smaller subset of beneficiaries had both an ID and DD diagnosis (0.4%). The percentage of beneficiaries with an ID/DD diagnosis declined with age—from 6.4% among ages 2-18 to 0.5% among ages 65 and older. Considering eight additional conditions that could be used to expand the baseline ID/DD definition in the future, we found that a diagnosis of cerebral palsy had the highest likelihood of a co-occurring baseline ID/DD condition (53.2%), followed by those with other chromosomal abnormalities (47.9%) and speech and language disorders (37.6%). The findings also showed a disproportionately high prevalence of some conditions in the 2-18 age group, but lower co-occurrence with baseline ID/DD conditions—particularly for conditions like ADHD and speech and language disorders.

TEP members emphasized that the high prevalence of certain conditions among children may reflect diagnostic practices shaped by access to and eligibility for services, clinical uncertainty, or clinical bias rather than a true indication of ID/DD. For example, ADHD is often diagnosed in childhood in part because it provides access to educational or behavioral support services. Similarly, speech and language disorders are often identified early in life in response to developmental concerns, though such diagnoses may not persist into adulthood. TEP members also described how billing practices influence which diagnoses appear on claims, with clinicians often listing only the primary reason for a visit. As a result, co-occurring ID/DD may not be consistently coded, particularly when the primary clinical concern is unrelated to intellectual or developmental functioning. For instance, a child with cerebral palsy and intellectual disability who is being treated for motor deficits may have claims coded only for cerebral palsy, even if they also meet criteria for ID. These patterns may help partially explain why we observed a general decline in co-occurrence of baseline ID/DD conditions with the eight additional conditions among older adults.

As previously shown, adding the eight additional conditions to the ID/DD baseline definition would have varying impacts on population size. TEP members emphasized the importance of accounting for diagnostic and billing practices across the lifespan when considering any expansion to the definition. While there was general agreement that co-occurrence of other conditions with ID/DD is a meaningful approach for identifying other conditions to add to the baseline definition, future studies could consider a more formal, consensus-based approach involving ID/DD experts and those with lived experience to finalize the conditions for use in an expansion of the baseline definition. Future research could also build on the exploratory administrative data analysis conducted for this brief to further refine the identification of conditions. For example, we used only two years of data (2021-2022), which may be insufficient to capture certain types of conditions — particularly rare ones. Our data also covers the height of emergent health threats, when Medicaid/CHIP enrollment was at historically high levels¹⁶; potentially creating bias in the prevalence estimates for the population under age 65. Future studies could replicate or test these findings using a longer analytic window and/or using data from years prior to 2020 or from the period following the end of the emergent health threats. Finally, while we used a large population of Medicare and Medicaid beneficiaries, those with private insurance, military and veteran health coverage, or who were uninsured (self-pay) were not included. Expanding the analysis to include all-payer claims databases, commercial insurance claims, or using charts or clinical data linked to administrative data would make such analyses more representative of the national population.

Once a list of conditions for more comprehensively defining the ID/DD population in claims is finalized, the next step could be to revise the current CCW flags accordingly, and test and validate the revised version. This would entail careful selection of parameters such as the lookback period for claims-based analysis, care setting, and types of claims or encounters to be analyzed. For example, it is common for certain specialty conditions (e.g., diabetes) to specify criteria such as two or more outpatient claims but only one inpatient claim in order to be included in a claims-based definition. TEP members also emphasized the importance of considering tradeoffs between sensitivity and specificity when considering updates to the baseline definition. A narrow definition of ID/DD will be less sensitive but more specific, and therefore reduce the risk of including individuals who do not have ID/DD but may not include individuals that do have ID/DD. Some TEP members also suggested developing separate claims-based definitions for children (aged 18 years and under) versus adults. They also noted that to maximize the utility of any revised ID/DD definition, it would be important to offer specific guidance for use (e.g., suggesting adaptations for varying research objectives) and establish processes for ongoing updates based on evolving knowledge about ID/DD and updates to ICD-10 diagnosis codes and other potential crosswalks or equivalency mappings.

This work represents an important step toward improving how ID/DD is identified in administrative data, offering a preliminary yet practical foundation for future refinement. By grounding the analysis in both administrative data and expert insights, this research highlights both the promise and the complexity of expanding beyond the current ID/DD operational definitions. As future work continues to seek more accurate representations of the ID/DD population, ongoing refinement of the conditions included, validation of claims-based parameters, and stakeholder engagement will be essential.

References

- ¹Tassé MJ, Havercamp SM, Krahn G, et al. About Whom Are We Talking When We Use Intellectual and Developmental Disabilities? *JAMA Pediatr.* 2025;179(1):83–89. doi:10.1001/jamapediatrics.2024.4552
- ²McMahon, Martin, and Chris Hatton. "A comparison of the prevalence of health problems among adults with and without intellectual disability: A total administrative population study." *Journal of Applied Research in Intellectual Disabilities* 34.1 (2021): 316-325.
- ³Hayden MF, Kim S, DePaepe P. Health status, utilization patterns, and outcomes of persons with intellectual disabilities: Review of the literature. *Mental Retardation.* 2005;43:175–195. doi: 10.1352/0047-6765(2005)43[175:HSUPAO]2.0.CO;2.
- ⁴Krahn GL, Fox MH. Health disparities of adults with intellectual disabilities: what do we know? What do we do? *J Appl Res Intellect Disabil.* 2014 Sep;27(5):431-46. doi: 10.1111/jar.12067. Epub 2013 Jul 31. PMID: 23913632; PMCID: PMC4475843.
- ⁵Rubenstein E, Tewolde S, Levine AA, Droscha L, Meyer RM, Michals A, Skotko B. Medicare, Medicaid, and dual enrollment for adults with intellectual and developmental disabilities. *Health Serv Res.* 2024 Jun;59(3):e14287. doi:10.1111/1475-6773.14287. PubMed. PMCID: PMC11063084. Accessed August 8, 2025.
- ⁶Medicaid and CHIP Payment and Access Commission (MACPAC). Access in Brief: Differences in Demographics and Access to Care by Source of Health Coverage for Adults with Intellectual and Developmental Disabilities. June 26, 2025. Washington, DC: MACPAC. Accessed August 8, 2025. <https://www.macpac.gov/wp-content/uploads/2025/06/Access-in-Brief-Differences-in-Demographics-and-Access-for-Adults-with-IDD.pdf>
- ⁷Johnston KJ, Hendricks M, Dabas M, Macneal E, Jung J, Meyers DJ, Figueroa JF, Roberts ET. Nationwide availability of and enrollment in Medicare and Medicaid dual-eligible special needs plans with exclusively aligned enrollment. *JAMA Health Forum.* 2024 Oct; 5(10):e243546. doi:10.1001/jamahealthforum.2024.3546. Accessed August 8, 2025.
- ⁸Centers for Medicare & Medicaid Services. *Condition categories.* Chronic Conditions Warehouse. <https://www2.ccwdata.org/web/guest/condition-categories>
- ⁹Sommers, A., Chiri, G., Rios, N., Hayes, M., Plourde, E., Karimi, M., & Reichard, A. Operationalizing the Definition of Intellectual and Developmental Disabilities in Administrative Claims Data for Research (Issue Brief). Washington, DC: Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. December 30, 2023.

- ¹⁰ Centers for Medicare & Medicaid Services. *Other chronic health, mental health, and potentially disabling conditions*. Chronic Conditions Data Warehouse. Retrieved May 22, 2025, from <https://www2.ccwdata.org/web/guest/condition-categories-other>
- ¹¹ Developmental surveillance and screening of infants and young children. *Pediatrics*. 2001 Jul;108(1):192-6. doi: 10.1542/peds.108.1.192. PMID: 11433077.
- ¹² Rice, C. E., Van Naarden Braun, K., Kogan, M. D., Smith, C., Kavanagh, L., Strickland, B., & Blumberg, S. J. (2009). Screening for developmental delays among young children — National Survey of Children's Health, United States, 2007. *Morbidity and Mortality Weekly Report*, 58(SS-6), 1–35. <https://www.cdc.gov/mmwr/preview/mmwrhtml/su6302a5.htm>
- ¹³ Elias R, Lord C. Diagnostic stability in individuals with autism spectrum disorder: insights from a longitudinal follow-up study. *J Child Psychol Psychiatry*. 2022 Sep;63(9):973-983. doi: 10.1111/jcpp.13551. Epub 2021 Dec 10. PMID: 34890046; PMCID: PMC9502651.
- ¹⁴ Landes, S.D., McDonald, K.E., Wilmoth, J.M. and Carter Grosso, E. (2021), Evidence of continued reduction in the age-at-death disparity between adults with and without intellectual and/or developmental disabilities. *J Appl Res Intellect Disabil*, 34: 916-920. <https://doi.org/10.1111/jar.12840>
- ¹⁵ Shea LL, Field R, Xie M, Marcus S, Newschaffer C, Mandell D. Transition-Age Medicaid Coverage for Adolescents With Autism and Adolescents With Intellectual Disability. *Am J Intellect Dev Disabil*. 2019 Mar;124(2):174-185. doi: 10.1352/1944-7558-124.2.174. PMID: 30835524; PMCID: PMC10726726.
- ¹⁶ Centers for Medicare & Medicaid Services. December 2022 Medicaid & CHIP Enrollment Trend Snapshot. December 2022. Available at: <https://www.medicaid.gov/medicaid/national-medicaid-chip-program-information/downloads/December-2022-medicaid-chip-enrollment-trend-snapshot.pdf>. Accessed June 26, 2025.

Appendix A: ICD-10 Codes Used in the Baseline ID/DD Definition, Mapped to 6 Condition Categories

Table A1: ICD-10 Codes Used in the Baseline ID/DD Definition, Mapped to 6 Condition Categories

ID/DD Condition	ICD-10 Codes	Description	Clinical Classifications Software Refined (CCSR) Category
Intellectual Disabilities			
Intellectual Disabilities	E7871	Barth Syndrome	Other specified and unspecified nutritional and metabolic disorders
	E7872	Smith-Lemli-Opitz syndrome	Other specified and unspecified nutritional and metabolic disorders
	F70	Mild intellectual disabilities	Neurodevelopmental disorders
	F71	Moderate intellectual disabilities	Neurodevelopmental disorders
	F72	Severe intellectual disabilities	Neurodevelopmental disorders
	F73	Profound intellectual disabilities	Neurodevelopmental disorders
	F78	Other intellectual disabilities	Neurodevelopmental disorders
	F78A	Other genetic related intellectual disabilities	None
	F78A1	SYNGAP1-related intellectual disability	Neurodevelopmental disorders
	F78A9	Other genetic related intellectual disability	Neurodevelopmental disorders
F79	Unspecified intellectual disabilities	Neurodevelopmental disorders	
Congenital Malformations of the Nervous System	Q8789	Other specified congenital malformation syndromes, not elsewhere classified	Other specified and unspecified congenital anomalies
	Q897	Multiple congenital malformations, not elsewhere classified	Other specified and unspecified congenital anomalies
	Q898	Other specified congenital malformations	Other specified and unspecified congenital anomalies
Other Congenital Malformations and Chromosomal Anomalies	Q871	Congenital malformation syndromes predominantly associated with short stature	Other specified and unspecified congenital anomalies
	Q8711	Prader-Willi syndrome	Other specified and unspecified congenital anomalies
	Q8719	Other congenital malformation syndromes predominantly associated with short stature	Other specified and unspecified congenital anomalies

ID/DD Condition	ICD-10 Codes	Description	Clinical Classifications Software Refined (CCSR) Category
	Q872	Congenital malformation syndromes predominantly involving limbs	Other specified and unspecified congenital anomalies
	Q873	Congenital malformation syndromes involving early overgrowth	Other specified and unspecified congenital anomalies
	Q875	Other congenital malformation syndromes with other skeletal changes	Other specified and unspecified congenital anomalies
	Q8781	Alport syndrome	Other specified and unspecified congenital anomalies
	Q8783	Bardet-Biedl syndrome	None
	Q8784	Laurence-Moon syndrome	None
	Q8785	MED13L syndrome	None
	Q910	Trisomy 18, nonmosaicism (meiotic nondisjunction)	Chromosomal abnormalities
	Q911	Trisomy 18, mosaicism (mitotic nondisjunction)	Chromosomal abnormalities
	Q912	Trisomy 18, translocation	Chromosomal abnormalities
	Q913	Trisomy 18, unspecified	Chromosomal abnormalities
	Q914	Trisomy 13, nonmosaicism (meiotic nondisjunction)	Chromosomal abnormalities
	Q915	Trisomy 13, mosaicism (mitotic nondisjunction)	Chromosomal abnormalities
	Q916	Trisomy 13, translocation	Chromosomal abnormalities
	Q917	Trisomy 13, unspecified	Chromosomal abnormalities
	Q920	Whole chromosome trisomy, nonmosaicism (meiotic nondisjunction)	Chromosomal abnormalities
	Q921	Whole chromosome trisomy, mosaicism (mitotic nondisjunction)	Chromosomal abnormalities
	Q922	Partial trisomy	Chromosomal abnormalities
	Q925	Duplications with other complex rearrangements	Chromosomal abnormalities
	Q926	Marker chromosomes	Chromosomal abnormalities
	Q9261	Marker chromosomes in normal individual	Chromosomal abnormalities
	Q9262	Marker chromosomes in abnormal individual	Chromosomal abnormalities

ID/DD Condition	ICD-10 Codes	Description	Clinical Classifications Software Refined (CCSR) Category
	Q927	Triploidy and polyploidy	Chromosomal abnormalities
	Q928	Other specified trisomies and partial trisomies of autosomes	Chromosomal abnormalities
	Q929	Trisomy and partial trisomy of autosomes, unspecified	Chromosomal abnormalities
	Q930	Whole chromosome monosomy, nonmosaicism (meiotic nondisjunction)	Chromosomal abnormalities
	Q931	Whole chromosome monosomy, mosaicism (mitotic nondisjunction)	Chromosomal abnormalities
	Q932	Chromosome replaced with ring, dicentric or isochromosome	Chromosomal abnormalities
	Q933	Deletion of short arm of chromosome 4	Chromosomal abnormalities
	Q934	Deletion of short arm of chromosome 5	Chromosomal abnormalities
	Q935	Other deletions of part of a chromosome	Chromosomal abnormalities
	Q9351	Angelman syndrome	Chromosomal abnormalities
	Q9352	Phelan-McDermid syndrome	None
	Q9359	Other deletions of part of a chromosome	Chromosomal abnormalities
	Q937	Deletions with other complex rearrangements	Chromosomal abnormalities
	Q938	Other deletions from the autosomes	Chromosomal abnormalities
	Q9381	Velo-cardio-facial syndrome	Chromosomal abnormalities
	Q9382	Williams syndrome	Chromosomal abnormalities
	Q9388	Other microdeletions	Chromosomal abnormalities
	Q9389	Other deletions from the autosomes	Chromosomal abnormalities
	Q939	Deletion from autosomes, unspecified	Chromosomal abnormalities
	Q952	Balanced autosomal rearrangement in abnormal individual	Chromosomal abnormalities
	Q953	Balanced sex/autosomal rearrangement in abnormal individual	Chromosomal abnormalities
	Q992	Fragile X chromosome	Chromosomal abnormalities

ID/DD Condition	ICD-10 Codes	Description	Clinical Classifications Software Refined (CCSR) Category
Down Syndrome	Q90	Down syndrome	Chromosomal abnormalities
	Q900	Trisomy 21, nonmosaicism (meiotic nondisjunction)	Chromosomal abnormalities
	Q901	Trisomy 21, mosaicism (mitotic nondisjunction)	Chromosomal abnormalities
	Q902	Trisomy 21, translocation	Chromosomal abnormalities
	Q909	Down syndrome, unspecified	Chromosomal abnormalities
Fetal alcohol syndrome	Q860	Fetal alcohol syndrome (dysmorphic)	Newborn affected by maternal conditions or complications of labor/delivery
	P043	Newborn affected by maternal use of alcohol	Newborn affected by maternal conditions or complications of labor/delivery
Developmental Disabilities			
Pervasive and Specific Developmental Disorders	F819	Developmental disorder of scholastic skills, unspecified	Neurodevelopmental disorders
	F82	Specific developmental disorder of motor function	Neurodevelopmental disorders
	F840	Autistic disorder	Neurodevelopmental disorders
	F842	Rett's syndrome	Neurodevelopmental disorders
	F843	Other childhood disintegrative disorder	Neurodevelopmental disorders
	F845	Asperger's syndrome	Neurodevelopmental disorders
	F848	Other pervasive developmental disorders	Neurodevelopmental disorders
	F849	Pervasive developmental disorder, unspecified	Neurodevelopmental disorders
	F88	Other disorders of psychological development	Neurodevelopmental disorders
	F89	Unspecified disorder of psychological development	Neurodevelopmental disorders

Appendix B1: ICD-10 Codes for Eight Additional Conditions Selected for Administrative Data Analysis and that Can be Considered for an Expansion of the Baseline ID/DD Definition

Table B1: ICD-10 Codes for Eight Additional Conditions of Interest

ICD-10 Code	Diagnosis Code Description	Condition Category
F900	Attention-deficit hyperactivity disorder, predominantly inattentive type	ADHD
F901	Attention-deficit hyperactivity disorder, predominantly hyperactive type	ADHD
F902	Attention-deficit hyperactivity disorder, combined type	ADHD
F908	Attention-deficit hyperactivity disorder, other type	ADHD
F909	Attention-deficit hyperactivity disorder, unspecified type	ADHD
F911	Conduct disorder, childhood-onset type	ADHD
F912	Conduct disorder, adolescent-onset type	ADHD
F913	Oppositional defiant disorder	ADHD
F918	Other conduct disorders	ADHD
F919	Conduct disorder, unspecified	ADHD
G80	Cerebral palsy	Cerebral Palsy
G800	Spastic quadriplegic cerebral palsy	Cerebral Palsy
G801	Spastic diplegic cerebral palsy	Cerebral Palsy
G802	Spastic hemiplegic cerebral palsy	Cerebral Palsy
G803	Athetoid cerebral palsy	Cerebral Palsy
G804	Ataxic cerebral palsy	Cerebral Palsy
G808	Other cerebral palsy	Cerebral Palsy
G809	Cerebral palsy, unspecified	Cerebral Palsy
F81	Specific developmental disorders of scholastic skills	Learning Disabilities
F810	Specific reading disorder	Learning Disabilities
F812	Mathematics disorder	Learning Disabilities
F818	Other developmental disorders of scholastic skills	Learning Disabilities
F8181	Disorder of written expression	Learning Disabilities
F8189	Other developmental disorders of scholastic skills	Learning Disabilities
R480	Dyslexia and alexia	Learning Disabilities
Q950	Balanced translocation and insertion in normal individual	Other Chromosomal Abnormalities
Q951	Chromosome inversion in normal individual	Other Chromosomal Abnormalities
Q955	Individual with autosomal fragile site	Other Chromosomal Abnormalities
Q958	Other balanced rearrangements and structural markers	Other Chromosomal Abnormalities
Q959	Balanced rearrangement and structural marker, unspecified	Other Chromosomal Abnormalities

ICD-10 Code	Diagnosis Code Description	Condition Category
Q960	Karyotype 45, X	Other Chromosomal Abnormalities
Q961	Karyotype 46, X iso (Xq)	Other Chromosomal Abnormalities
Q962	Karyotype 46, X with abnormal sex chromosome, except iso (Xq)	Other Chromosomal Abnormalities
Q963	Mosaicism, 45, X/46, XX or XY	Other Chromosomal Abnormalities
Q964	Mosaicism, 45, X/other cell line(s) with abnormal sex chromosome	Other Chromosomal Abnormalities
Q968	Other variants of Turner's syndrome	Other Chromosomal Abnormalities
Q969	Turner's syndrome, unspecified	Other Chromosomal Abnormalities
Q970	Karyotype 47, XXX	Other Chromosomal Abnormalities
Q971	Female with more than three X chromosomes	Other Chromosomal Abnormalities
Q972	Mosaicism, lines with various numbers of X chromosomes	Other Chromosomal Abnormalities
Q973	Female with 46, XY karyotype	Other Chromosomal Abnormalities
Q978	Other specified sex chromosome abnormalities, female phenotype	Other Chromosomal Abnormalities
Q979	Sex chromosome abnormality, female phenotype, unspecified	Other Chromosomal Abnormalities
Q980	Klinefelter syndrome karyotype 47, XXY	Other Chromosomal Abnormalities
Q981	Klinefelter syndrome, male with more than two X chromosomes	Other Chromosomal Abnormalities
Q983	Other male with 46, XX karyotype	Other Chromosomal Abnormalities
Q984	Klinefelter syndrome, unspecified	Other Chromosomal Abnormalities
Q985	Karyotype 47, XYY	Other Chromosomal Abnormalities
Q986	Male with structurally abnormal sex chromosome	Other Chromosomal Abnormalities
Q987	Male with sex chromosome mosaicism	Other Chromosomal Abnormalities
Q988	Other specified sex chromosome abnormalities, male phenotype	Other Chromosomal Abnormalities
Q989	Sex chromosome abnormality, male phenotype, unspecified	Other Chromosomal Abnormalities
Q990	Chimera 46, XX/46, XY	Other Chromosomal Abnormalities
Q991	46, XX true hermaphrodite	Other Chromosomal Abnormalities
Q998	Other specified chromosome abnormalities	Other Chromosomal Abnormalities
Q999	Chromosomal abnormality, unspecified	Other Chromosomal Abnormalities
Q791	Other congenital malformations of diaphragm	Other Congenital Anomalies
Q851	Tuberous sclerosis	Other Congenital Anomalies
Q858	Other phakomatoses, not elsewhere classified	Other Congenital Anomalies
Q8581	PTEN hamartoma tumor syndrome	Other Congenital Anomalies
Q8582	Other Cowden syndrome	Other Congenital Anomalies
Q8583	Von Hippel-Lindau syndrome	Other Congenital Anomalies

ICD-10 Code	Diagnosis Code Description	Condition Category
Q8589	Other phakomatoses, not elsewhere classified	Other Congenital Anomalies
Q874	Marfan syndrome	Other Congenital Anomalies
Q8740	Marfan syndrome, unspecified	Other Congenital Anomalies
Q8741	Marfan syndrome with cardiovascular manifestations	Other Congenital Anomalies
Q87410	Marfan syndrome with aortic dilation	Other Congenital Anomalies
Q87418	Marfan syndrome with other cardiovascular manifestations	Other Congenital Anomalies
Q8742	Marfan syndrome with ocular manifestations	Other Congenital Anomalies
Q8743	Marfan syndrome with skeletal manifestation	Other Congenital Anomalies
Q878	Other specified congenital malformation syndromes, not elsewhere classified	Other Congenital Anomalies
Q8782	Arterial tortuosity syndrome	Other Congenital Anomalies
Q890	Congenital absence and malformations of spleen	Other Congenital Anomalies
Q8901	Asplenia (congenital)	Other Congenital Anomalies
Q8909	Congenital malformations of spleen	Other Congenital Anomalies
Q891	Congenital malformations of adrenal gland	Other Congenital Anomalies
Q892	Congenital malformations of other endocrine glands	Other Congenital Anomalies
Q893	Situs inversus	Other Congenital Anomalies
Q894	Conjoined twins	Other Congenital Anomalies
Q899	Congenital malformation, unspecified	Other Congenital Anomalies
G113	Cerebellar ataxia with defective DNA repair	Other Nervous System Disorders
G318	Other specified degenerative diseases of nervous system	Other Nervous System Disorders
G3180	Leukodystrophy, unspecified	Other Nervous System Disorders
G3181	Alpers disease	Other Nervous System Disorders
G3182	Leigh's disease	Other Nervous System Disorders
G3183	Neurocognitive disorder with Lewy bodies	Other Nervous System Disorders
G3184	Mild cognitive impairment of uncertain or unknown etiology	Other Nervous System Disorders
G3185	Corticobasal degeneration	Other Nervous System Disorders
G3186	Alexander disease	Other Nervous System Disorders
G3189	Other specified degenerative diseases of nervous system	Other Nervous System Disorders
G319	Degenerative disease of nervous system, unspecified	Other Nervous System Disorders
G708	Other specified myoneural disorders	Other Nervous System Disorders
G7080	Lambert-Eaton syndrome, unspecified	Other Nervous System Disorders
G7081	Lambert-Eaton syndrome in disease classified elsewhere	Other Nervous System Disorders
G7089	Other specified myoneural disorders	Other Nervous System Disorders
G731	Lambert-Eaton syndrome in neoplastic disease	Other Nervous System Disorders
G938	Other specified disorders of brain	Other Nervous System Disorders
G9381	Temporal sclerosis	Other Nervous System Disorders

ICD-10 Code	Diagnosis Code Description	Condition Category
G9382	Brain death	Other Nervous System Disorders
G9389	Other specified disorders of brain	Other Nervous System Disorders
G939	Disorder of brain, unspecified	Other Nervous System Disorders
F80	Specific developmental disorders of speech and language	Speech and Language Disorders
F800	Phonological disorder	Speech and Language Disorders
F801	Expressive language disorder	Speech and Language Disorders
F802	Mixed receptive-expressive language disorder	Speech and Language Disorders
F804	Speech and language development delay due to hearing loss	Speech and Language Disorders
F808	Other developmental disorders of speech and language	Speech and Language Disorders
F8081	Childhood onset fluency disorder	Speech and Language Disorders
F8082	Social pragmatic communication disorder	Speech and Language Disorders
F8089	Other developmental disorders of speech and language	Speech and Language Disorders
F809	Developmental disorder of speech and language, unspecified	Speech and Language Disorders
H9325	Central auditory processing disorder	Speech and Language Disorders
G901	Familial dysautonomia [Riley-Day]	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q000	Anencephaly	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q001	Craniorachischisis	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q002	Iniencephaly	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q010	Frontal encephalocele	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q011	Nasofrontal encephalocele	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q012	Occipital encephalocele	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q018	Encephalocele of other sites	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q019	Encephalocele, unspecified	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q02	Microcephaly	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q030	Malformations of aqueduct of Sylvius	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q031	Atresia of foramina of Magendie and Luschka	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q038	Other congenital hydrocephalus	Spina Bifida and Other Congenital Anomalies of the Nervous System

ICD-10 Code	Diagnosis Code Description	Condition Category
Q039	Congenital hydrocephalus, unspecified	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q04	Other congenital malformations of brain	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q040	Congenital malformations of corpus callosum	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q041	Arhinencephaly	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q042	Holoprosencephaly	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q043	Other reduction deformities of brain	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q044	Septo-optic dysplasia of brain	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q045	Megalencephaly	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q046	Congenital cerebral cysts	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q048	Other specified congenital malformations of brain	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q049	Congenital malformation of brain, unspecified	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q050	Cervical spina bifida with hydrocephalus	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q051	Thoracic spina bifida with hydrocephalus	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q052	Lumbar spina bifida with hydrocephalus	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q053	Sacral spina bifida with hydrocephalus	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q054	Unspecified spina bifida with hydrocephalus	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q055	Cervical spina bifida without hydrocephalus	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q056	Thoracic spina bifida without hydrocephalus	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q057	Lumbar spina bifida without hydrocephalus	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q058	Sacral spina bifida without hydrocephalus	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q059	Spina bifida, unspecified	Spina Bifida and Other Congenital Anomalies of the Nervous System

ICD-10 Code	Diagnosis Code Description	Condition Category
Q060	Amyelia	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q061	Hypoplasia and dysplasia of spinal cord	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q062	Diastematomyelia	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q063	Other congenital cauda equina malformations	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q064	Hydromyelia	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q068	Other specified congenital malformations of spinal cord	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q069	Congenital malformation of spinal cord, unspecified	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q070	Arnold-Chiari syndrome	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q0700	Arnold-Chiari syndrome without spina bifida or hydrocephalus	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q0701	Arnold-Chiari syndrome with spina bifida	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q0702	Arnold-Chiari syndrome with hydrocephalus	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q0703	Arnold-Chiari syndrome with spina bifida and hydrocephalus	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q078	Other specified congenital malformations of nervous system	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q079	Congenital malformation of nervous system, unspecified	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q861	Fetal hydantoin syndrome	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q868	Other congenital malformation syndromes due to known exogenous causes	Spina Bifida and Other Congenital Anomalies of the Nervous System
Q870	Congenital malformation syndromes predominantly affecting facial appearance	Spina Bifida and Other Congenital Anomalies of the Nervous System

Appendix B2: ICD-10 Codes for Seven Conditions Not Selected for Administrative Data Analysis but that Can be Considered for an Expansion of the Baseline ID/DD Definition

Table B2. ICD-10 Codes for Seven Conditions Not Selected for Administrative Data Analysis

ICD-10 Code	Diagnosis Code Description	Condition Category
F938	Other childhood emotional disorders	Behavioral Health Disorders
F939	Childhood emotional disorder, unspecified	Behavioral Health Disorders
F941	Reactive attachment disorder of childhood	Behavioral Health Disorders
F948	Other childhood disorders of social functioning	Behavioral Health Disorders
F988	Other specified behavioral and emotional disorders with onset usually occurring in childhood and adolescence	Behavioral Health Disorders
F989	Unspecified behavioral and emotional disorders with onset usually occurring in childhood and adolescence	Behavioral Health Disorders
P000	Newborn affected by maternal hypertensive disorders	Conditions Affecting Newborns
P001	Newborn affected by maternal renal and urinary tract diseases	Conditions Affecting Newborns
P002	Newborn affected by maternal infectious and parasitic diseases	Conditions Affecting Newborns
P003	Newborn affected by other maternal circulatory and respiratory diseases	Conditions Affecting Newborns
P004	Newborn affected by maternal nutritional disorders	Conditions Affecting Newborns
P005	Newborn affected by maternal injury	Conditions Affecting Newborns
P006	Newborn affected by surgical procedure on mother	Conditions Affecting Newborns
P007	Newborn affected by other medical procedures on mother, not elsewhere classified	Conditions Affecting Newborns
P008	Newborn affected by other maternal conditions	Conditions Affecting Newborns
P0081	Newborn affected by periodontal disease in mother	Conditions Affecting Newborns
P0082	Newborn affected by (positive) maternal group B streptococcus (GBS) colonization	Conditions Affecting Newborns
P0089	Newborn affected by other maternal conditions	Conditions Affecting Newborns
P009	Newborn affected by unspecified maternal condition	Conditions Affecting Newborns
P041	Newborn affected by other maternal medication	Conditions Affecting Newborns
P0411	Newborn affected by maternal antineoplastic chemotherapy	Conditions Affecting Newborns
P0412	Newborn affected by maternal cytotoxic drugs	Conditions Affecting Newborns
P0413	Newborn affected by maternal use of anticonvulsants	Conditions Affecting Newborns
P0414	Newborn affected by maternal use of opiates	Conditions Affecting Newborns

ICD-10 Code	Diagnosis Code Description	Condition Category
P0415	Newborn affected by maternal use of antidepressants	Conditions Affecting Newborns
P0416	Newborn affected by maternal use of amphetamines	Conditions Affecting Newborns
P0417	Newborn affected by maternal use of sedative-hypnotics	Conditions Affecting Newborns
P0418	Newborn affected by other maternal medication	Conditions Affecting Newborns
P0419	Newborn affected by maternal use of unspecified medication	Conditions Affecting Newborns
P041A	Newborn affected by maternal use of anxiolytics	Conditions Affecting Newborns
P044	Newborn affected by maternal use of drugs of addiction	Maternal Use of Drugs
P0440	Newborn affected by maternal use of unspecified drugs of addiction	Maternal Use of Drugs
P0441	Newborn affected by maternal use of cocaine	Maternal Use of Drugs
P0442	Newborn affected by maternal use of hallucinogens	Maternal Use of Drugs
P0449	Newborn affected by maternal use of other drugs of addiction	Maternal Use of Drugs
P048	Newborn affected by other maternal noxious substances	Maternal Use of Drugs
P0481	Newborn affected by maternal use of cannabis	Maternal Use of Drugs
P0489	Newborn affected by other maternal noxious substances	Maternal Use of Drugs
P049	Newborn affected by maternal noxious substance, unspecified	Maternal Use of Drugs
F063	Mood disorder due to known physiological condition	Mental Health Conditions
F0630	Mood disorder due to known physiological condition, unspecified	Mental Health Conditions
F0631	Mood disorder due to known physiological condition with depressive features	Mental Health Conditions
F0632	Mood disorder due to known physiological condition with major depressive-like episode	Mental Health Conditions
F0633	Mood disorder due to known physiological condition with manic features	Mental Health Conditions
F0634	Mood disorder due to known physiological condition with mixed features	Mental Health Conditions
F200	Paranoid schizophrenia	Mental Health Conditions
F201	Disorganized schizophrenia	Mental Health Conditions
F202	Catatonic schizophrenia	Mental Health Conditions
F205	Residual schizophrenia	Mental Health Conditions
F208	Other schizophrenia	Mental Health Conditions
F2081	Schizophreniform disorder	Mental Health Conditions

ICD-10 Code	Diagnosis Code Description	Condition Category
F2089	Other schizophrenia	Mental Health Conditions
F209	Schizophrenia, unspecified	Mental Health Conditions
F21	Schizotypal disorder	Mental Health Conditions
F22	Delusional disorders	Mental Health Conditions
F23	Brief psychotic disorder	Mental Health Conditions
F24	Shared psychotic disorder	Mental Health Conditions
F259	Schizoaffective disorder, unspecified	Mental Health Conditions
F28	Other psychotic disorder not due to a substance or known physiological condition	Mental Health Conditions
F29	Unspecified psychosis not due to a substance or known physiological condition	Mental Health Conditions
F320	Major depressive disorder, single episode, mild	Mental Health Conditions
F321	Major depressive disorder, single episode, moderate	Mental Health Conditions
F322	Major depressive disorder, single episode, severe without psychotic features	Mental Health Conditions
F323	Major depressive disorder, single episode, severe with psychotic features	Mental Health Conditions
F324	Major depressive disorder, single episode, in partial remission	Mental Health Conditions
F325	Major depressive disorder, single episode, in full remission	Mental Health Conditions
F329	Major depressive disorder, single episode, unspecified	Mental Health Conditions
F330	Major depressive disorder, recurrent, mild	Mental Health Conditions
F331	Major depressive disorder, recurrent, moderate	Mental Health Conditions
F332	Major depressive disorder, recurrent severe without psychotic features	Mental Health Conditions
F333	Major depressive disorder, recurrent, severe with psychotic symptoms	Mental Health Conditions
F334	Major depressive disorder, recurrent, in remission	Mental Health Conditions
F3340	Major depressive disorder, recurrent, in remission, unspecified	Mental Health Conditions
F3341	Major depressive disorder, recurrent, in partial remission	Mental Health Conditions
F3342	Major depressive disorder, recurrent, in full remission	Mental Health Conditions
F339	Major depressive disorder, recurrent, unspecified	Mental Health Conditions
F340	Cyclothymic disorder	Mental Health Conditions
F341	Dysthymic disorder	Mental Health Conditions
F400	Agoraphobia	Mental Health Conditions
F4000	Agoraphobia, unspecified	Mental Health Conditions

ICD-10 Code	Diagnosis Code Description	Condition Category
F4001	Agoraphobia with panic disorder	Mental Health Conditions
F4002	Agoraphobia without panic disorder	Mental Health Conditions
F401	Social phobias	Mental Health Conditions
F4010	Social phobia, unspecified	Mental Health Conditions
F4011	Social phobia, generalized	Mental Health Conditions
F402	Specific (isolated) phobias	Mental Health Conditions
F4021	Animal type phobia	Mental Health Conditions
F40210	Arachnophobia	Mental Health Conditions
F40218	Other animal type phobia	Mental Health Conditions
F4022	Natural environment type phobia	Mental Health Conditions
F40220	Fear of thunderstorms	Mental Health Conditions
F40228	Other natural environment type phobia	Mental Health Conditions
F4023	Blood, injection, injury type phobia	Mental Health Conditions
F40230	Fear of blood	Mental Health Conditions
F40231	Fear of injections and transfusions	Mental Health Conditions
F40232	Fear of other medical care	Mental Health Conditions
F40233	Fear of injury	Mental Health Conditions
F4024	Situational type phobia	Mental Health Conditions
F40240	Claustrophobia	Mental Health Conditions
F40241	Acrophobia	Mental Health Conditions
F40242	Fear of bridges	Mental Health Conditions
F40243	Fear of flying	Mental Health Conditions
F40248	Other situational type phobia	Mental Health Conditions
F4029	Other specified phobia	Mental Health Conditions
F40290	Androphobia	Mental Health Conditions
F40291	Gynephobia	Mental Health Conditions
F40298	Other specified phobia	Mental Health Conditions
F408	Other phobic anxiety disorders	Mental Health Conditions
F409	Phobic anxiety disorder, unspecified	Mental Health Conditions
F410	Panic disorder [episodic paroxysmal anxiety]	Mental Health Conditions
F411	Generalized anxiety disorder	Mental Health Conditions
F418	Other specified anxiety disorders	Mental Health Conditions
F419	Anxiety disorder, unspecified	Mental Health Conditions
F422	Mixed obsessional thoughts and acts	Mental Health Conditions
F423	Hoarding disorder	Mental Health Conditions
F428	Other obsessive-compulsive disorder	Mental Health Conditions
F429	Obsessive-compulsive disorder, unspecified	Mental Health Conditions

ICD-10 Code	Diagnosis Code Description	Condition Category
F431	Post-traumatic stress disorder (PTSD)	Mental Health Conditions
F4310	Post-traumatic stress disorder, unspecified	Mental Health Conditions
F4311	Post-traumatic stress disorder, acute	Mental Health Conditions
F4312	Post-traumatic stress disorder, chronic	Mental Health Conditions
F432	Adjustment disorders	Mental Health Conditions
F4320	Adjustment disorder, unspecified	Mental Health Conditions
F4321	Adjustment disorder with depressed mood	Mental Health Conditions
F4322	Adjustment disorder with anxiety	Mental Health Conditions
F4323	Adjustment disorder with mixed anxiety and depressed mood	Mental Health Conditions
F4324	Adjustment disorder with disturbance of conduct	Mental Health Conditions
F4325	Adjustment disorder with mixed disturbance of emotions and conduct	Mental Health Conditions
F4329	Adjustment disorder with other symptoms	Mental Health Conditions
F438	Other reactions to severe stress	Mental Health Conditions
F4381	Prolonged grief disorder	Mental Health Conditions
F4389	Other reactions to severe stress	Mental Health Conditions
F440	Dissociative amnesia	Mental Health Conditions
F441	Dissociative fugue	Mental Health Conditions
F444	Conversion disorder with motor symptom or deficit	Mental Health Conditions
F446	Conversion disorder with sensory symptom or deficit	Mental Health Conditions
F448	Other dissociative and conversion disorders	Mental Health Conditions
F4481	Dissociative identity disorder	Mental Health Conditions
F4489	Other dissociative and conversion disorders	Mental Health Conditions
F449	Dissociative and conversion disorder, unspecified	Mental Health Conditions
F450	Somatization disorder	Mental Health Conditions
F451	Undifferentiated somatoform disorder	Mental Health Conditions
F452	Hypochondriacal disorders	Mental Health Conditions
F4520	Hypochondriacal disorder, unspecified	Mental Health Conditions
F4521	Hypochondriasis	Mental Health Conditions
F4522	Body dysmorphic disorder	Mental Health Conditions
F4529	Other hypochondriacal disorders	Mental Health Conditions
F458	Other somatoform disorders	Mental Health Conditions
F459	Somatoform disorder, unspecified	Mental Health Conditions
F481	Depersonalization-derealization syndrome	Mental Health Conditions
F488	Other specified nonpsychotic mental disorders	Mental Health Conditions
F489	Nonpsychotic mental disorder, unspecified	Mental Health Conditions

ICD-10 Code	Diagnosis Code Description	Condition Category
F600	Paranoid personality disorder	Mental Health Conditions
F601	Schizoid personality disorder	Mental Health Conditions
F602	Antisocial personality disorder	Mental Health Conditions
F603	Borderline personality disorder	Mental Health Conditions
F604	Histrionic personality disorder	Mental Health Conditions
F605	Obsessive-compulsive personality disorder	Mental Health Conditions
F606	Avoidant personality disorder	Mental Health Conditions
F607	Dependent personality disorder	Mental Health Conditions
F608	Other specific personality disorders	Mental Health Conditions
F6081	Narcissistic personality disorder	Mental Health Conditions
F6089	Other specific personality disorders	Mental Health Conditions
F609	Personality disorder, unspecified	Mental Health Conditions
F681	Factitious disorder imposed on self	Mental Health Conditions
F6810	Factitious disorder imposed on self, unspecified	Mental Health Conditions
F6811	Factitious disorder imposed on self, with predominantly psychological signs and symptoms	Mental Health Conditions
F6812	Factitious disorder imposed on self, with predominantly physical signs and symptoms	Mental Health Conditions
F6813	Factitious disorder imposed on self, with combined psychological and physical signs and symptoms	Mental Health Conditions
F688	Other specified disorders of adult personality and behavior	Mental Health Conditions
F930	Separation anxiety disorder of childhood	Mental Health Conditions
F940	Selective mutism	Mental Health Conditions
F99	Mental disorder, not otherwise specified	Mental Health Conditions
E75	Disorders of sphingolipid metabolism and other lipid storage disorders	Metabolic Disorders
E750	GM2 gangliosidosis	Metabolic Disorders
E7500	GM2 gangliosidosis, unspecified	Metabolic Disorders
E7501	Sandhoff disease	Metabolic Disorders
E7502	Tay-Sachs disease	Metabolic Disorders
E7509	Other GM2 gangliosidosis	Metabolic Disorders
E751	Other and unspecified gangliosidosis	Metabolic Disorders
E7510	Unspecified gangliosidosis	Metabolic Disorders
E7511	Mucopolipidosis IV	Metabolic Disorders
E7519	Other gangliosidosis	Metabolic Disorders
E752	Other sphingolipidosis	Metabolic Disorders
E7521	Fabry (-Anderson) disease	Metabolic Disorders

ICD-10 Code	Diagnosis Code Description	Condition Category
E7522	Gaucher disease	Metabolic Disorders
E7523	Krabbe disease	Metabolic Disorders
E7524	Niemann-Pick disease	Metabolic Disorders
E75240	Niemann-Pick disease type A	Metabolic Disorders
E75241	Niemann-Pick disease type B	Metabolic Disorders
E75242	Niemann-Pick disease type C	Metabolic Disorders
E75243	Niemann-Pick disease type D	Metabolic Disorders
E75244	Niemann-Pick disease type A/B	Metabolic Disorders
E75248	Other Niemann-Pick disease	Metabolic Disorders
E75249	Niemann-Pick disease, unspecified	Metabolic Disorders
E7525	Metachromatic leukodystrophy	Metabolic Disorders
E7526	Sulfatase deficiency	Metabolic Disorders
E7527	Pelizaeus-Merzbacher disease	Metabolic Disorders
E7528	Canavan disease	Metabolic Disorders
E7529	Other sphingolipidosis	Metabolic Disorders
E753	Sphingolipidosis, unspecified	Metabolic Disorders
E754	Neuronal ceroid lipofuscinosis	Metabolic Disorders
E755	Other lipid storage disorders	Metabolic Disorders
E756	Lipid storage disorder, unspecified	Metabolic Disorders
E76	Disorders of glycosaminoglycan metabolism	Metabolic Disorders
E760	Mucopolysaccharidosis, type I	Metabolic Disorders
E7601	Hurler's syndrome	Metabolic Disorders
E7602	Hurler-Scheie syndrome	Metabolic Disorders
E7603	Scheie's syndrome	Metabolic Disorders
E761	Mucopolysaccharidosis, type II	Metabolic Disorders
E762	Other mucopolysaccharidoses	Metabolic Disorders
E7621	Morquio mucopolysaccharidoses	Metabolic Disorders
E76210	Morquio A mucopolysaccharidoses	Metabolic Disorders
E76211	Morquio B mucopolysaccharidoses	Metabolic Disorders
E76219	Morquio mucopolysaccharidoses, unspecified	Metabolic Disorders
E7622	Sanfilippo mucopolysaccharidoses	Metabolic Disorders
E7629	Other mucopolysaccharidoses	Metabolic Disorders
E763	Mucopolysaccharidosis, unspecified	Metabolic Disorders
E768	Other disorders of glucosaminoglycan metabolism	Metabolic Disorders
E769	Glucosaminoglycan metabolism disorder, unspecified	Metabolic Disorders
E77	Disorders of glycoprotein metabolism	Metabolic Disorders

ICD-10 Code	Diagnosis Code Description	Condition Category
E770	Defects in post-translational modification of lysosomal enzymes	Metabolic Disorders
E771	Defects in glycoprotein degradation	Metabolic Disorders
E778	Other disorders of glycoprotein metabolism	Metabolic Disorders
E779	Disorder of glycoprotein metabolism, unspecified	Metabolic Disorders
E787	Disorders of bile acid and cholesterol metabolism	Metabolic Disorders
E7870	Disorder of bile acid and cholesterol metabolism, unspecified	Metabolic Disorders
E7879	Other disorders of bile acid and cholesterol metabolism	Metabolic Disorders
E791	Lesch-Nyhan syndrome	Metabolic Disorders
E798	Other disorders of purine and pyrimidine metabolism	Metabolic Disorders
E7981	Aicardi-Goutieres syndrome	Metabolic Disorders
E7982	Hereditary xanthinuria	Metabolic Disorders
E7989	Other specified disorders of purine and pyrimidine metabolism	Metabolic Disorders
E830	Disorders of copper metabolism	Metabolic Disorders
E8300	Disorder of copper metabolism, unspecified	Metabolic Disorders
E8301	Wilson's disease	Metabolic Disorders
E8309	Other disorders of copper metabolism	Metabolic Disorders
E888	Other specified metabolic disorders	Metabolic Disorders
E8881	Metabolic syndrome and other insulin resistance	Metabolic Disorders
E88810	Metabolic syndrome	Metabolic Disorders
E88811	Insulin resistance syndrome, Type A	Metabolic Disorders
E88818	Other insulin resistance	Metabolic Disorders
E88819	Insulin resistance, unspecified	Metabolic Disorders
E8889	Other specified metabolic disorders	Metabolic Disorders
S049XXS	Injury of unspecified cranial nerve, sequela	Nerve Injuries
S069X9S	Unspecified intracranial injury with loss of consciousness of unspecified duration, sequela	Nerve Injuries
S14109S	Unspecified injury at unspecified level of cervical spinal cord, sequela	Nerve Injuries
S142XXS	Injury of nerve root of cervical spine, sequela	Nerve Injuries
S149XXS	Injury of unspecified nerves of neck, sequela	Nerve Injuries
S24109S	Unspecified injury at unspecified level of thoracic spinal cord, sequela	Nerve Injuries
S242XXS	Injury of nerve root of thoracic spine, sequela	Nerve Injuries
S249XXS	Injury of unspecified nerve of thorax, sequela	Nerve Injuries

ICD-10 Code	Diagnosis Code Description	Condition Category
S34109S	Unspecified injury to unspecified level of lumbar spinal cord, sequela	Nerve Injuries
S34139S	Unspecified injury to sacral spinal cord, sequela	Nerve Injuries
S3421XS	Injury of nerve root of lumbar spine, sequela	Nerve Injuries
S3422XS	Injury of nerve root of sacral spine, sequela	Nerve Injuries
S349XXS	Injury of unspecified nerves at abdomen, lower back and pelvis level, sequela	Nerve Injuries
S4490XS	Injury of unspecified nerve at shoulder and upper arm level, unspecified arm, sequela	Nerve Injuries
S5490XS	Injury of unspecified nerve at forearm level, unspecified arm, sequela	Nerve Injuries
S6490XS	Injury of unspecified nerve at wrist and hand level of unspecified arm, sequela	Nerve Injuries
S7490XS	Injury of unspecified nerve at hip and thigh level, unspecified leg, sequela	Nerve Injuries
S8490XS	Injury of unspecified nerve at lower leg level, unspecified leg, sequela	Nerve Injuries
S9490XS	Injury of unspecified nerve at ankle and foot level, unspecified leg, sequela	Nerve Injuries
G838	Other specified paralytic syndromes	Paralysis
G8381	Brown-Sequard syndrome	Paralysis
G8382	Anterior cord syndrome	Paralysis
G8383	Posterior cord syndrome	Paralysis
G8384	Todd's paralysis (postepileptic)	Paralysis
G8389	Other specified paralytic syndromes	Paralysis

Appendix C: Co-Occurrence of Each of the Eight Additional Conditions with ID Versus DD in the Baseline Definition

Table C1. Co-Occurrence of Each of the Eight Additional Conditions with ID Versus DD in the Baseline Definition

Condition Category	Overall			Children (2-18)			Adults (19-64)			Older Adults (65+)		
	N	Co-occurrence with ID- only	Co-occurrence with DD- only	N	Co-occurrence with ID-only	Co-occurrence with DD- only	N	Co-occurrence with ID-only	Co-occurrence with DD- only	N	Co-occurrence with ID-only	Co-occurrence with DD- only
ADHD	5,073,667	4.9%	14.2%	2,984,238	3.5%	19.0%	1,666,657	8.0%	9.0%	422,772	1.9%	1.2%
Cerebral Palsy	438,186	40.2%	26.9%	109,593	28.2%	56.4%	262,929	48.6%	19.5%	65,664	27.0%	7.2%
Chromosomal Abnormalities	113,069	32.4%	34.9%	54,493	43.3%	60.3%	30,718	36.9%	20.8%	27,858	6.1%	0.6%
Learning Disabilities	278,453	9.2%	29.6%	232,406	6.2%	30.9%	30,960	32.1%	30.6%	15,087	9.4%	7.9%
Other Congenital Anomalies	156,627	11.5%	8.5%	37,419	16.3%	23.3%	49,402	16.7%	8.7%	69,806	5.2%	0.5%
Other Nervous System Disorders	4,741,118	2.2%	1.5%	72,559	15.3%	39.2%	674,236	9.0%	4.3%	3,994,323	0.8%	0.3%
Speech/Language Disorders	2,583,331	8.1%	34.7%	2,383,233	6.8%	35.9%	101,517	42.8%	37.5%	98,581	4.4%	2.2%
Spina Bifida	370,701	17.9%	18.7%	118,811	23.6%	43.3%	156,288	22.4%	10.8%	95,602	3.4%	1.1%