ASPE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION

OFFICE OF BEHAVIORAL HEALTH, DISABILITY, AND AGING POLICY

ISSUE BRIEF

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OPERATIONALIZING THE DEFINITION OF INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN ADMINISTRATIVE CLAIMS DATA FOR RESEARCH

KEY POINTS

- The application of multiple operational definitions for intellectual and developmental disabilities (ID/DD) in analyses of administrative claims data for health services and public health research limits translation of study findings to inform policies, programs, and practice.
- Using administrative claims data, researchers operationally define ID/DD and major subpopulations using diagnosis codes from the International Classification of Diseases-Ninth Revision, Clinical Modification (ICD-9-CM) and Tenth Revision (ICD-10-CM).
- Health services and public health research studies have rarely provided a well-defined rationale for the inclusion or exclusion of individual diagnoses or conditions in operational definitions of ID/DD.
- Further work is needed to establish a standard conceptual definition with which to align diagnostic codes, as well as to understand the implications of inclusion and exclusion of conditions from operational definitions.
- ICD codes are designed for medical billing and administrative purposes rather than research studies. This misalignment poses challenges to research efforts.
- Operationalizing the definition for ID/DD should include input from individuals with an ID/DD, researchers, and clinicians.

BACKGROUND

In 2018, an estimated 7.4 million people with intellectual and developmental disabilities (ID/DD) lived in the United States.[1] Population surveillance research has highlighted wide variation in prevalence estimates of ID/DD in the population due to different methodologies, data sources, and lack of a standard definition for ID/DD applied in research.[2,3] Health services and public health research on the ID/DD population and subpopulations has prioritized building foundational knowledge of the health-related characteristics of the ID/DD population, including the root causes for and correlates to key indicators of comorbidity, mortality, functional status, health behaviors, health care utilization, access, and related outcomes.[4] However, the differences in defining which conditions comprise the ID/DD population have led to inconsistencies in the evidence base about the health-related characteristics of the population.

In 2011, the Eunice Kennedy Shriver Center at the University of Massachusetts Medical School convened national experts to examine conceptual and operational definitions for intellectual disability (ID) and developmental disability (DD).[5] They developed a multidimensional framework for ID and DD, and explained differences in operational definitions used across federal agencies, state programs, and the International Classification of Disease (ICD) and Classification of Functioning, Disability and Health. Two distinct definitions inform federal agencies. One definition of ID is specified by the American Association on Intellectual and

Developmental Disabilities, and a second definition of DD is specified by the Developmental Disability Act (DD Act) (see ***text box***). These conceptual definitions are intended to describe what conditions meet the criteria for inclusion as part of the ID/DD population, but it is still unclear which specific conditions should be used to operationally define the ID/DD population. Definitions of DD continue to evolve, as does capacity to collect and analyze data.[6] Federal agencies are subject to statutory mandates that define the populations they serve and data they must collect. As a result of agency requirements defined in statute, research conducted by a specific agency may focus on either ID or DD populations rather than both populations.

> ***Intellectual disability (ID)*** *is a condition characterized by significant limitations in both intellectual functioning and adaptive behavior that originates before age 22.*[7]
> ***Developmental disability (DD)*** *is a severe, chronic disability due to a mental or physical impairment originating before age 22. DD is likely to continue throughout the lifespan, results in substantial functional limitations in major life activities, and reflects an individual's need for a combination of services and supports.*[8]

National population surveys have not included questions that allow researchers to identify individuals with ID/DD, which limits the use of these data to understand the ID/DD population.[9] Research using data from government programs that tie eligibility for services to a narrow definition of ID or DD may not be generalizable to a broader ID/DD population.[4] As a result, health care administrative claims have become an important data source for studying health-related characteristics of individuals with ID/DD and their health outcomes. Health care claims data capture large and diverse population samples and can help researchers examine the healthcare diagnoses and utilization patterns of individuals with ID/DD and people who do not have ID/DD.[10,11,12] However, claims data are subject to other sources of bias because they are only representative of people enrolled in health care or insurance programs and contain limited information about cognitive and functional limitations, which are key dimensions for defining ID and DD. Individuals with ID/DD are primarily identified using diagnoses classified in ICD-Ninth Revision, Clinical Modification (ICD-9-CM) and ICD-Tenth Revision, Clinical Modification (ICD-10-CM) codes.[a,13,14] However, there is no consensus on what diagnostic codes should be used to identify the ID/DD population.

In prior work, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) solicited insights from key informants, experts and people with lived experience for the purpose of identifying and prioritizing opportunities to improve patient-centered outcomes research data infrastructure that addresses the needs of individuals with ID/DD. Through a listening session and interviews, informants prioritized developing a standardized definition of ID/DD and indicated that experts should develop a list of ICD-10-CM codes and other criteria that could be used to develop a data flag to identify individuals with ID/DD in Medicare, T-MSIS, and other data sets that use ICD-10-CM codes.[15] For this study, ASPE aims to better understand variation in the selection of ICD-9 and ICD-10 diagnostic codes and corresponding ID/DD conditions for operationalizing ID/DD in administrative claims data research as a first step to: (1) develop a consensus-based, standardized conceptual definition of ID/DD; and (2) operationalize this definition for use in health services and public health research.

RESEARCH QUESTIONS

Through this research, ASPE aims to address the following key research questions.

[a] ICD-10 utilizes a code format which combines both letters and numbers. They include a letter plus two digits to the left of the decimal point, then 1-2 digits to the right. ICD-9-CM codes are mostly numeric and have 3-5 digits. In both systems, the first digits represent the general category, and the numbers after the period are for subcategories.

1. How do relevant federal agencies operationally define ID/DD when conducting analyses of administrative claims data?
2. How have studies published in peer-reviewed literature operationally defined ID/DD to identify the population in administrative claims data?
3. How do the operational definitions of the ID/DD population used in peer-reviewed literature and federal agencies compare and contrast?
4. What is the rationale for inclusion and exclusion of individual diagnoses or conditions in operational definitions of the ID/DD population identified in selected research studies?
5. What are the implications for inclusion and exclusion of certain conditions in an ID/DD population operational definition in administrative claims data for research?

ASPE commissioned RTI International to conduct an environmental scan and comparative analysis across peer-reviewed literature and government sources of operational definitions using administrative claims data to identify the ID/DD population in health services research. To address research Questions 4 and 5, RTI interviewed authors of selected peer-reviewed articles, as well as clinical practice experts and experts from the U.S. Department of Health and Human Services (HHS).

METHODS

Federal Definition Review

ASPE staff requested a list of ICD-9 and ICD-10 codes used to define the ID/DD population in research activities from the following divisions and institutes within HHS:

- Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Division of Human Development and Disability.
- Centers for Medicare & Medicaid Services (CMS), Centers for Medicaid and CHIP Services, Disability and Elderly Health Programs, Division of Community Systems Transformation.
- ASPE, Office of Behavioral Health, Disability, and Aging Policy.
- Administration for Community Living, National Institute on Disability, Independent Living, and Rehabilitation Research.
- National Institute of Health, National Institute of Mental Health, Eunice Kennedy Shriver National Institute of Child Health and Human Development.

We also reviewed two government resources that are cited by some researchers as the source of their diagnostic codes were included in the review: Clinical Classification Software (CCS) and Chronic Conditions Data Warehouse (CCW). The CCS is a tool for clustering ICD-9 and ICD-10 diagnostic and procedure codes into a manageable number of clinically meaningful categories developed by the Health Care Utilization Project (HCUP), Agency for Health Care Research and Quality.[16] The CCW, maintained by CMS, uses algorithms to identify 30 chronic conditions and 40 potentially disabling condition categories in Medicare and Medicaid administrative claims data.[17] Although both the CCS and CCW include some conditions considered to be ID/DD conditions, such as Autism Spectrum Disorder, neither source provides a standard conceptual or operational definition for the ID/DD population.

Literature Scan

The scan examined studies published in peer-reviewed literature or by agencies within HHS with study populations defined as having “intellectual disabilities and/or developmental disabilities”. Research studies that included a narrow set of conditions or specific disorders (i.e., Down syndrome) were excluded from the scan unless the broader ID/DD population was included in analysis as a comparison population. The scan also identified studies using administrative health care claims data and diagnostic codes to identify the ID/DD

population. The review was limited to English-language articles or reports published between January 2018 and August 2022. Research that did not use ICD-9 or ICD-10 codes to identify the ID/DD population (i.e., relied exclusively on eligibility for a program) were excluded. A total of 61 articles met criteria for review. (***Appendix B-1*** provides full citations for all 61 articles)

Comparative Analysis

The ICD-9 and ICD-10 codes that were used to define the population of people with ID/DD in each study were examined and compared to determine frequency of inclusion and exclusion of certain conditions codes in an ID/DD population operational definition. For articles listing a range of codes rather than individual codes, the range was compared to the CMS ICD-9 and ICD-10 databases[18] and valid individual codes were extracted.

Key Informant Interviews

A total of eight interviews were conducted with federal and non-federal key informants engaged in ID/DD research using administrative claims data. In one of these interviews, two key informants were present. Interviews were prioritized with the lead authors of studies identified in the environmental scan who developed the most commonly cited operational definitions. Interviews were also conducted with HHS experts to understand the inclusion and exclusion criteria from federal working operational definitions of ID/DD. Lastly, RTI conducted interviews with two clinical experts to help understand the difference between diagnostic and functional definitions of ID/DD and explore why researchers might include or exclude specific disorders from an ID/DD construct applied in health services research.

FINDINGS

Results of the Environmental Scan (RQs 1-3)

RESEARCH QUESTION 1: How do relevant federal agencies operationally define ID/DD when conducting analyses of administrative claims data?

Federal agencies provided two different operational definitions that they have used to identify the population of people with ID/DD when conducting analyses for health services or public health research. ***Appendix Table A-1*** summarizes the major condition categories captured by each operational definition. The agency definitions are identified as Federal Agency Definitions #1 and #2. A complete list of the individual ICD-9 and ICD-10 codes used in the two operational definitions are presented in ***Appendix Table A-2***. The list of codes provided for Definition #1 contained both ICD-9 and ICD-10 codes, whereas Definition #2 contained only ICD-10 codes.

Operational Definitions of ID/DD Used by Federal Agencies

Agency Definition #1 used CCW condition groups to form the ID/DD operational definition and consists of a total of six condition groups from the CCW to identify ID/DD:

- Learning Disabilities.
- Intellectual Disabilities and Related Conditions.
- Autism Spectrum Disorders.
- Other Developmental Delays.
- Spina Bifida and Other Congenital Anomalies of the Nervous System.
- Cerebral Palsy.

The two operational definitions used by federal agencies are closely aligned; both federal definitions included the same codes for:

- Intellectual Disabilities and Related Conditions.
- Cerebral Palsy.
- Congenital Malformations of the Nervous System, except Spina Bifida.
- Down Syndrome.
- Fetal Alcohol Syndrome.

Both federal operational definitions include individual codes in the category of Other Congenital Malformation or Nervous System Disorder Not Otherwise Classified (NEC) indicating specific syndromes:

- Q99.2 (Fragile X chromosome, Chromosomal Anomaly).
- Q871 (Aarrskog, Prader-Willi syndrome, de Lange, Seckel, etc.).
- Q878.1 (Alport Syndrome).
- Q878.9 (Other specified congenital malformation syndromes, not elsewhere classified).

The two federal definitions differ in their inclusion of a few diagnostic codes selected under the ICD-10 classifications of Intellectual Disabilities and Pervasive and Specific Developmental Disabilities. Within the category of Pervasive and Specific Developmental Disorders, Definition #1 includes the following codes that were excluded from Definition #2:

- F81.9, F82 (Other Developmental Delays).
- F84.8, F84.9 (Other pervasive DD, pervasive DD, unspecified).

Definition #2 includes two codes omitted in Definition #1:

- G31.81 (Alpers disease).
- Q85.1 (Tuberous sclerosis).

The major difference between the two is that Definition #1 includes the subcategories of Learning Disabilities and Spina Bifida.

RESEARCH QUESTION 2: How have studies published in peer-reviewed literature operationally defined intellectual and developmental disabilities to identify the population in administrative claims data?

Sources for Operational Definitions in Peer-Reviewed Literature

Of the 61 articles reviewed, 49 articles directly referenced 14 articles between them as the sources for operational definitions. Methodologies for the 14 articles referenced were reviewed, resulting in another ten articles referenced by these articles as the source for their definition. These 24 articles are listed in ***Appendix B-2*** and referred to here as source articles. Source articles that met inclusion criteria for the literature review also appear in ***Appendix B-1***.

The review found several patterns in citation practices. First, research teams frequently referenced other research teams as the origin for a set of diagnostic codes. Second, the articles cited as sources were not always the origin for the code set. As examples:

- Clements et al. (2020) and Rebbe et al. (2021) cite Mitra et al. (2018a), which cites Mitra et al. (2015)19 as the origin of the codes.
- Lunsky et al. (2013)[20] is the origin for codes used by Lin et al. (2013).[21] Lin et al. (2013) is cited by 12 other articles, including Darney et al. (2017),[22] which is cited by two other articles in the review (Nishat et al. [2022] and Tarasoff et al. [2020]).

Ultimately four research teams were most frequently the origin of diagnostic code sets:

- Lin et al. (2013) and Lunsky et al. (2013) were cited by 23 articles.
- McDermott et al. (2018) in the review was cited by 11 articles.
- Mitra et al. (2015, 2018a, 2019) were cited by nine articles.
- Parish et al. (2015)[23] was cited by six articles.

The methods used by these four research teams were replicated to define ID/DD for 45 studies identified in the scan. The definition used by Lin et al. (2013) and Lunksy et al. (2013), which were cited by 23 articles, come from the same research team in Ontario, Canada. Nine articles cited Mitra and colleagues (2015, 2018a, 2019) and share a common diagnostic code list, except 299.02, which is an ICD-8 code for autism autistic disorder not included in later ICD versions and is used only by Mitra et al. (2015). Some articles cited more than one of these sources. ***Appendix Table A-3*** lists each article included in the review and which source the authors referenced for their diagnostic codes, including the article originating the code set, if not directly cited.

Thirteen articles did not cite a source for operational definitions, but differed in the code set used by others. ***Appendix Table A-4*** lists these articles. Six articles used condition groups supplied by the CCW (Cyrus et al. [2019], Reichard et al. [2019], and McDermott et al. [2018]) or the HCUP CCS (Zandam et al. [2022], Brown et al. [2021], and Parish et al. [2018]).

Operational Definitions of ID/DD in Peer-Reviewed Literature

Given that four research teams informed code sets for two-thirds of the articles reviewed, the diagnostic code sets from these four studies were compared. The ICD-9 and ICD-10 codes included in each definition are presented in ***Appendix Table A-2*** alongside the agency definitions.

The four studies include two published by Canadian research teams (Lin et al. [2013] and Lunsky et al. [2013]) and two published by research teams in the United States (McDermott et al. [2018] and Mitra et al. [2015]). Notably, the code lists of Lin et al. (2013) and Lunsky et al. (2013) differ slightly in that Lin et al. (2013) includes one ICD-10 code for spina bifida (G90.1), whereas Lunsky et al. (2013) includes a list of syndromes under the category of Congenital Malformations of the Nervous System not included in Lin et al. (2013). Studies originating from the Lin et al. [2013} and Lunsky et al. [2013] teams excluded conditions in the category of Cerebral Degeneration Manifested in Childhood.

Across all 61 studies, about one-fourth of the studies included codes for cerebral palsy. Of the studies using ICD-9 codes to define this condition, codes were identical across studies except for 333.71 (Athetoid cerebral palsy), which two studies excluded and instead used ICD-9 code 333 (Other degenerative diseases of the basal ganglia). About one-third of studies included codes in the category of Cerebral Degenerations Manifested in Childhood other than the Cerebral Palsy code series and varied in the codes used. About one-half of these studies included only 330.8 (Other specified cerebral degenerations in childhood) and 330 (which is not a valid code itself but might serve to capture all 330 codes), whereas the other half included some (not all) codes in the 330 series (330.0, 330.1, 330.2, 330.3, 330.8, 330.9), with 330.8 more commonly used than others. Only one study (Whittingham et al., 2020) using ICD-10 codes included the E75 series, which is generally equivalent to the ICD-9 330 series.

General equivalency mapping was used to assign ICD-9 and ICD-10 codes to a shared subclassification or classification. After excluding classifications that did not involve a genetic, hereditary, or potentially disabling condition (see ***Additional Methodologies***), 190 pairs of ICD-9 and ICD-10 codes remained that theoretically could contribute to a wider operational definition for ID/DD. These codes fell into two groups with divergent features. The first group consisted of ICD-10 codes falling into categories which also include common ID/DD conditions (e.g., chromosomal anomalies). Examples include congenital, hereditary muscular dystrophy,

leukodystrophy, and congenital rubella. The second group consisted of ICD-10 codes for conditions that were the consequence of either genetic, external, or unspecified causes which manifest as a disability, loss of function, low cognitive or physical function. Examples include deformities, blindness, deafness, spinal cord injuries, paralysis, head injuries, loss of limbs, and crushing injuries.

RESEARCH QUESTION 3: How do the operational definitions of ID/DD used in studies published in peer-reviewed literature and those used by federal agencies compare and contrast?

We compared the operational definitions used most in the literature to those used by federal agencies (see ***Appendix Tables A-1*** and ***A-2***). The commonly used operational definitions in the published literature and the federal agency definitions included the same diagnostic codes in three ICD-9/ICD-10 categories:

- Intellectual Disabilities (317-319, F70-F79).
- Pervasive and Specific Developmental Disorders (299.9-299.999, F80-F89), inclusive of Autism Spectrum Disorder.
- Fetal Alcohol Syndrome (760.71, 760.77, P04.3, Q86.0, Q86.1).

Similar to Agency Definition #2, the peer-reviewed literature operational definitions did not include Learning Disabilities. Code sets in McDermott et al. (2018) and Mitra et al. (2015) aligned with both federal agency definitions because they included Cerebral Degenerations Manifested in Childhood, inclusive of Cerebral Palsy, whereas the studies using Canadian data did not. These differences might be related to the objective of authors studying population health in Ontario, who aimed to align the ID/DD definition with populations eligible for an income support program. Authors using government data available in the United States studied populations enrolled in state Medicaid programs and Medicare. Differences in the inclusion of conditions in United States studies could reflect variation in the conditions associated with program eligibility rules across state Medicaid programs and Medicare.

The peer-reviewed literature differed from the federal agency definitions in the identification of other diagnostic categories. Specifically, only one peer-reviewed article (Reichard et al. 2019) included the broader set of codes for Intellectual Disabilities described as "Related Conditions" in the CCW, which were included in both Agency Definitions. To define Down Syndrome, Lin et al. (2013) excluded diagnoses for extra marker chromosomes from the definition (Q92.6, Q97.1, A99.2, Q99.8, Q90.0-Q93.9), whereas both agency definitions, Lunsky et al. (2013) and other studies included Q92.61, Q92.62 and Q95.2 (Marker chromosomes in normal individuals, Marker chromosomes in abnormal individuals, and Fragile X chromosome, respectively).

Findings from the Key Informant Interviews (RQs 4-5)

RESEARCH QUESTION 4: What is the rationale for inclusion and exclusion of individual diagnoses or conditions in operational definitions of the ID/DD population identified in research studies?

Conceptualization of ID/DD

Key informants were prompted to elaborate on their general conceptualization of ID/DD as distinguished and separate from the actual operationalization used in their work. One commonly recurring conceptualization was the "functional definition." Key informants used this term to refer to conditions marked by substantial and enduring disability arising from a mental or physical impairment, or combination of these impairments. They noted the condition must also lead to notable limitations in essential aspects of everyday life activities and be anticipated to be present throughout a person's life. They also stressed the developmental origin of the condition. This interpretation aligns with the definition of developmental disabilities found within the DD Act and the Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5), although only two key informants explicitly referenced these sources as the foundation of their interpretation.

Two of the experts who adhered to a functional understanding of ID/DD, indicated that cognitive limitations were integrated into their conceptualization of the ID/DD population. One expert specifically noted a generally positive association between cognitive function and adaptive skills, although occasional deviations from this pattern occur.

Apart from one expert who emphasized that their conceptualization was notably shaped by regional legislation, the majority of key informants did not explicitly mention considerations about qualifying for state or federal assistance programs in their understanding of ID/DD.

The process of developing a conceptualization for ID/DD involved, in certain instances, extensive cooperation with either federal or regional authorities, stakeholder groups, and scholarly engagement with fellow researchers. A few individuals mentioned relying on existing research to shape their comprehension of ID/DD and did not engage in extensive collaborative endeavors with peers or outside groups. Clinical experts interviewed were also informed by their deep understanding of their patients, the range of cognitive and functional skill levels observed among patients with the same diagnosis, and the expected range in independent living in adulthood among individuals with the same diagnosis.

Inclusion of Groups of Conditions and Specific Diagnostic Codes

Key informants were split on whether cerebral palsy should become part of a standard operational definition of ID/DD. Three experts believed cerebral palsy should be included, four did not, and one was ambivalent. A reason for including cerebral palsy was its high co-occurrence with ID. Those against its inclusion argued that cerebral palsy is an injury, something static, not developmental. Experts advanced similar arguments for and against the inclusion of spina bifida.[b] A key informant pointed out that cerebral palsy and spina bifida often induce relatively minor effects on functioning, and therefore suggested they should not be classified as an ID/DD. Contrastingly, another key informant offered that since both spina bifida and cerebral palsy are present at birth, they would influence an individual's developmental trajectory irrespective of any associated ID.

Key informants frequently brought up developmental delays, learning difficulties, and Attention-Deficit/Hyperactivity Disorder (ADHD) at the same time. For most, the decision to include or exclude them from a standardized operational definition stemmed from a shared rationale. This rationale hinged on determining if these conditions exert a lasting and significant influence across various key life domains over the long term, which should be an essential criterion for inclusion. One key informant cautioned against utilizing the developmental delay diagnosis as they believe it was better to await the formal diagnosis of either autism or ID. In their opinion, delay in development does not constitute a diagnostic classification; instead, it serves as a temporary diagnosis preceding the confirmation of an official diagnosis.

One of the clinical experts pointed out that the clinical community already has taken the step to broaden the ID/DD umbrella to be inclusive of neurodevelopmental disorders and has established these conditions under the title “Neurodevelopmental Disorders” in the DSM-5. Another respondent supported the incorporation of a wider array of conditions (such as ADHD) and endorsed the idea of utilizing a more extensive set of codes. The key informant also provided additional insight, noting that in their research, they had come across diagnostic codes for ADHD and learning disabilities in the records of older individuals. This underscored the importance of basing the use of such codes on empirical evidence rather than on prior knowledge and assumptions about the ID/DD population.

[b] Although both cerebral palsy and spina bifida are conditions that affect mobility and can have neurological implications, they have different underlying causes, symptoms, and diagnostic criteria.

Some key informants felt they lacked the appropriate expertise to offer guidance about some of the diagnoses under consideration that were of a more medical nature. As articulated by one of the interviewees, there exists a challenge related to ICD codes due to the limited understanding among researchers about these conditions, leading to their exclusion. For instance, while most respondents did not provide an opinion on congenital anomalies (e.g., anencephaly, microcephaly) or cerebral degenerations usually manifest in childhood (e.g., leukodystrophy), few suggested it was not necessary to include these conditions due to their low occurrence and shortened life expectancy.

RESEARCH QUESTION 5: What are the implications for inclusion and exclusion of certain conditions in an ID/DD population operational definition in administrative claims data for research?

A distinct implication that surfaced from the qualitative interviews is that harmonizing the functional conceptual framework used by the key informants with an operational definition based on ICD codes will likely prove difficult. First, key informants recognized that ICD codes are not always designed to capture the extent of a condition's severity. While certain conditions are unquestionably recognized for exerting a lasting and pervasive influence on various aspects of life, the same cannot be said for a portion of the conditions under investigation. Additionally, all key informants recognized the challenges that arise from employing a system intended for medical billing and administrative record keeping purposes, which may not align with the objectives of research studies.

Another implication stems from the omission of conditions that could potentially be linked to DD. Some respondents noted that researchers who opt not to incorporate conditions like cerebral palsy or spina bifida might be excluding a segment of the population affected by ID/DD. Conversely, those who opt to include cerebral palsy and spina bifida without further probing if additional conditions related to ID/DD are present, may dilute or bias the results of their study. Several key informants emphasized this dilemma and deliberated about potential trade-offs. Specifically, the discussion revolved around balancing the need for specificity (excluding all possible non-cases) vs sensitivity (including all possible cases). Depending on the reason for the study, researchers may decide to prioritize sensitivity or specificity, though it would be important to make this assumption explicit.

The consensus among all key informants was that the choice of diagnoses included in the operational ID/DD population definition may be directed by the research inquiries being pursued, such as determining eligibility for various programs, estimating prevalence, or conducting health surveillance. Additionally, the diagnoses could vary based on whether researchers are focusing on understanding individuals who might be susceptible to developmental issues, in which case, a broader range of conditions inclusive of unspecified DD might be warranted. All key informants wondered if the variability found in research regarding inclusion and exclusion choices might be attributed to methodological carelessness or simply a lack of clinical knowledge.

Limitations

This environmental scan was limited in its purpose to assessing the range of operational definitions of ID/DD used in health services and public health research and limited to peer-reviewed literature published between 2018 and 2022. Government definitions were limited to code sets in use within HHS that could be obtained with low effort. The scan also excluded studies limited to a single subpopulation of ID/DD, such as Down Syndrome. Exploring operational definitions from studies investigating a single diagnosis could provide additional information to inform a standard operational ID/DD definition.

Two limitations in these data prevented direct comparison of all codes in every study. In some datasets, four-digit, five-digit, and six-digit codes are collapsed into the common three-digit code to remove personally identifying information. Code sets comprised of three-digit codes cannot be directly compared to studies using trailing digits. Clinicians and ID/DD experts should compare ICD-9 and ICD-10 code sets for meaningful

differences within the ICD-10 category of Congenital Malformations Deformations, and Chromosomal Abnormalities due to the large number of ICD-9 codes in this category that were segmented into many ICD-10 codes reflecting more specific conditions.

The qualitative interviews involved only a limited number of experts and were intended as brief explorations to identify potential explanations for differences in ID/DD population operational definitions in health services research. The interviews exposed a range of perspectives that likely do not reflect the full range of perspectives held in research, clinical, and policy communities. Moreover, this research did not engage advocacy organizations. Thus, findings should be received as exploratory and not conclusive.

DISCUSSION

This study to inform development of a standard operational ID/DD population definition using administrative claims data is part of a broader effort by ASPE and federal partners to invest in data infrastructure, data capacity, and data quality for ID/DD research.[24] The literature review and environmental scan identified diagnosis groups and specific conditions that are treated inconsistently in the operationalization of ID/DD in health services research using administrative claims data. Interviews with researchers and clinical experts in ID/DD revealed different concepts of ID/DD and several major considerations that could inform the operationalization of ID/DD in claims-based research.

Environmental Scan

Based on the environmental scan, opportunities to expand upon this work to develop a consensus operational definition of ID/DD for identifying this population in administrative claims data are listed below (see ***Table 1***).

Key Informants

Key informants described their own conceptualization of ID/DD as having evolved over time in tandem with the evolution of concepts taking place within the clinical, research, and advocacy communities. They expect the evolution of ID/DD concepts to continue as genetic and biomedical research advance our understanding of the etiology of specific conditions, and expand our society's capabilities and services to support individuals with disabilities with adaptive technology and independent living models. Recognizing that so much has changed in how we think about ID/DD over the past two decades, some interviewees believed that a facilitated conversation about changing perspectives would be fruitful for both clinicians and researchers in progressing the research community toward decisions about a common set of strategies for operationalizing ID/DD informed by a coherent and clarified conceptualization of ID/DD.

Interviewees identified two conceptual definitions of ID/DD that could ground the operationalization of ID/DD in research in a commonly accepted conceptual framework. The first conceptual definition recognizes that an essential component of ID/DD is the impact of cognitive or physical impairments on an individual's capacity to function independently in adulthood. While a functional definition of ID/DD shifts the focus from clinical diagnosis to an individual's functional limitations and support needs, it is not detached from clinical diagnoses. Rather, it emphasizes the impact of intellectual and developmental challenges on a person's daily life and overall functioning. The ID/DD definition delineated in the DD Act is most congruent with a conceptual definition based on functional limitation. However, functional limitations are not measured reliably in administrative claims, which makes it challenging to incorporate functional criteria into an operational definition for the ID/DD population using claims. The trade-offs involved in selecting diagnoses for inclusion in an operational ID/DD population definition should be informed by closer examination of the clinical research and the objectives of the research.

Table 1. Opportunities for Action	
Finding	**Action Steps**
This environmental scan was not intended to be a comprehensive review of research on ID/DD populations.	Expand the scan to include gray literature, government reports and multiple databases. Include studies based on single diagnoses like cerebral palsy, Down syndrome, and autism spectrum disorders, and research using data other than administrative claims that provides related information.
Other parameters of an operational definition besides diagnostic codes can significantly impact a study population size and characteristics.[a]	Expand review of operational definitions to the algorithms applied to capture diagnostic codes in claims data (the look-back period, claim type, number of encounters in which the diagnosis must be present, etc.). Consider whether the larger algorithm should be part of a standard operational definition of ID/DD
The reviewed literature included little discussion of conceptual definitions of ID/DD. Differences in operational definitions could reflect differences in conceptual definitions for ID/DD, research objectives, or neither.	Explore conceptual definitions of ID/DD with stakeholders. Include in these discussions: researchers, clinicians, individuals with an ID/DD and people and groups representing other populations with other disabling conditions who could benefit from a modified conceptual definition for ID/DD. Consider the following questions: ▪ Who benefits from existing conceptual definitions of ID/DD and who is adversely affected by inclusion or exclusion of conditions from this definition? ▪ Does health services and public health research require a new conceptual definition of ID/DD to better serve communities that ID/DD research will impact?
Many ICD-9 and ICD-10 codes are only approximately equivalent to each other, limiting comparisons of operational definitions that relied on only one version.	Simplify future discussions about operational definitions by focusing on ICD-10 diagnostic codes. Expand review to the use of procedural codes and program eligibility information available in Medicare and Medicaid data. Consult clinicians for review of apparent discrepancies in coding strategies to determine where there are true differences.
About one-third of the studies included codes under Cerebral Degenerations Manifested in Childhood that were not within the cerebral palsy code series.	Engage in discussion with authors and experts on the following questions: ▪ How is the inclusion or exclusion of these conditions informed by a conceptual definition of ID/DD? ▪ Are there implications for other conditions and categories?
Authors emphasized the high proportion of the ID/DD population having more than one ID/DD diagnosis. Studies of individuals with co-occurring diagnoses could explore how eligibility for inclusion based on primary or secondary diagnoses impacts the study population.	Investigate and review literature for data about the intersection between diagnostic groups. Encourage researchers to include results from sensitivity analyses in publications to explore the following questions: ▪ How does omission of a set of diagnostic codes from the algorithm to identify individuals with an ID/DD change the study population size, composition, and outcomes? ▪ How does exclusion of a specific diagnosis change the study population size, composition, and outcomes?

Note:

a. Amir, N., Mitra, M., Leung, K., & Moore Simas, T.A. (2022). Complications following hysterectomy in women with intellectual and developmental disabilities. *Disability and Health Journal*, 15(1), 101213. https://doi.org/10.1016/j.dhjo.2021.101213.

ICM = International Classification of Diseases; ID/DD = intellectual and developmental disabilities.

The second perspective is that researchers should draw from clinical consensus on which diagnoses constitute ID/DD, which is reflected in the set of diagnoses corresponding to the title of Neurodevelopmental Disabilities in the DSM-5. By extension, inclusion of diagnoses with a neurodevelopmental etiology in research would align with clinical consensus. The use of the term “neurodevelopmental” is rare in the literature reviewed in this brief and is not explicitly discussed at a conceptual level by researchers. This suggests that clinical expertise could facilitate advancement of the concept in the research community.

Building on these conceptual definitions to derive a standard operational definition may be possible but would need to be explored with significant input from the clinical community, health services researchers, and

individuals with an ID/DD to ensure a coherent rationale for deviations from either the DSM-5 list or the definition in the DD Act.

Aside from pointing out difficulties associated with aligning conceptual definitions with a coding system designed for billing purposes, these interviews also unearthed a discussion around which conditions may be considered developmental disabilities. Experts in the ID/DD field may consider engaging in a robust discussion of which conditions at the periphery of the ID/DD definition may be considered developmental disabilities, and whether it may be beneficial to have multiple operational definitions of ID/DD that are specified for precise interpretation. Furthermore, when utilizing administrative claims, researchers have the potential to make significant contributions about operational definitions by assessing codes that denote limitations in functional status.

Conclusion

This study explored variation in ID/DD operational definitions to inform additional activities to develop a standardized operational ID/DD definition for research using administrative claims data. An accepted standardized operational definition of ID/DD in administrative claims data could improve the evidence base of health services and public health research by:

- Improving the generalizability of research and translation of results for policy.
- Accelerating person-centered outcomes research for this population.
- Informing future work to standardize definitions for other data sources, including administrative surveys and national surveillance systems.

Standardizing an operational definition may also help to accomplish some items identified by ASPE's 2022 Report,[15] including to:

- Help practitioners to capture ID/DD status at the point of care
- Make it easier to translate definitions to the electronic health record context, and to include them in data standards in future versions of U.S. Core Data for Interoperability Plus[25]
- Support in the development of standardized outcome metrics specific to the ID/DD population, and contribute to the establishment of longitudinal datasets.

As efforts to establish a standardized definition of ID/DD remain ongoing, it is imperative for researchers to transparently delineate and substantiate their diagnostic inclusion or exclusion criteria. This practice will ensure that readers and fellow researchers can assess the degree to which research findings can be effectively compared across various studies.

ADDITIONAL METHODOLOGICAL INFORMATION

Literature Scan

Our literature scan applied the following parameters to the search:

- Articles in PubMed published between January 2018 and August 2022.
- Articles published in journals in the United States, United Kingdom, Australia, or Canada.
- Articles published in the English language.
- Articles published from January 2018 to August 2022.
- Peer-reviewed articles that represent health services or public health research, excluding biomedical and genetical research.

Two strategies to search PubMed were applied. The first strategy searched the title, abstract, author keywords and Medical Subject Headings using the search:

- (ICD-9 OR ICD-10 OR administrative data OR Medicaid OR Medicare) AND (intellectual and developmental disability).

The second strategy searched all fields using the search:

- ("intellectual and developmental"[all fields]) AND ("administrative claims" OR Lauer OR Parish OR CDC OR Havercamp OR Reichard OR Phillips OR McDermott OR Mitra OR Lunsky OR Horner-Johnson).

The first search yielded 116 articles and the second 94 additional articles for a total of 210 articles (only 26 articles appeared in both searches). Two analysts screened the title and abstract of each article to identify relevant articles to be included in the full review. A senior analyst knowledgeable of research on the ID/DD population conducted a second review where two analysts did not agree or were unsure of the article's inclusion. This set of articles were then extracted for details on the study population, subpopulations, methods for identifying the population in claims, and study limitations. Based on review of extracted text, a second senior analyst removed articles that did not meet eligibility criteria based on study details.

Comparative Analysis

A list of all extracted codes was created and then formatted to match the CMS database.[16] Duplicates and decimal points were removed, and in some cases, zeroes were added or removed to arrive at the closest valid code. The process resulted in a series of digits for each ICD-9 code, omitting the decimal. All digits in the fourth, fifth, and sixth place represent the codes to the right of the decimal. For example, the code 33371 in the file represents ICD-9 code 333.71. Each unique code was matched to a code listed in the CMS database.

Prior to finalizing the codes for analysis, codes denoted by authors as identifying comorbidities or non-ID/DD populations were removed. A senior analyst reviewed remaining codes that were: (1) never used by government agencies or commonly cited source articles; and (2) used by one or more authors that did not reference a source for their operational definition. Based on the ICD-9 or ICD-10 classifications, some additional codes appeared to identify comorbidities, outcomes of interest, or non-ID/DD populations. Codes in the broad categories of neoplasms, cerebrovascular disease, endocrine disorders, disorders involving immune mechanism, and complications related to pregnancy and normal delivery were removed as a result. Other codes were retained for closer analysis.

APPENDIX A

Table A-1: Comparison of Diagnosis Codes Used to Identify ID/DD in Commonly Cited Sources and Federal Agency Definitions						
Classification	Most Commonly Cited Sources for ID/DD Codes				Federal Agency Definitions	
	Lin 2013	Lunsky 2013	McDermott 2018	Mitra 2015	Definition #1	Definition #2
Intellectual Disabilities	X	X	X	X	X	X
Intellectual Disabilities-Related Conditions			X	X	X	X
Cerebral Degenerations Manifested in Childhood			X	X		
Cerebral Palsy			X	X		
Pervasive and Specific Developmental Disabilities	X	X	X	X	X	X
Autism	X	X	X	X	X	X
Learning Disabilities					X	
Congenital Malformations of the Nervous System	X			X	X	
Spina Bifida and Other Congenital Anomalies of the Nervous System	X				X	
Chromosomal Anomalies	X	X	X	X	X	X
Down Syndrome	X	X	X	X	X	X
Other and Unspecified Congenital Anomalies		X	X	X		
Fetal Alcohol syndrome	X	X	X	X	X	X
Other Congenital Malformation or Nervous System Disorder	X	X			X	X

Source: RTI International, September 2022.

Notes: For complete citations of articles in this table, see ***Appendix Table B-2***.

Table A-2: Comparison of Diagnosis Codes Used to Identify Individuals with ID/DD in Commonly Cited Sources and Federal Agency Definitions						
Code Range	Most Commonly Cited Sources for ID/DD Codes				Federal Agency Definitions	
	Lin 2013	Lunsky 2013	McDermott 2018	Mitra 2015	Definition #1	Definition #2
Intellectual Disabilities	**X**	**X**	**X**	**X**	**X**	**X**
317-319 Mild, Other, or Unspecified Intellectual Disabilities	X	X	X	X		NA
E78.71-E78.2 Barth syndrome, Mixed hyperlipidemia			NA	NA	X	X
F70-F73 Mild to Profound Intellectual Disabilities			NA	NA	X	X
F78-F79 Other or Unspecified Intellectual Disabilities			NA	NA	X	X
F70-F79 Intellectual disabilities	X	X	NA	NA		
Intellectual Disabilities - Related Conditions					**X**	**X**
Q87.1, Q87.11, Q87.19, Q87.2, Q87.3, Q87.5, Q87.81, Q87.89 Other specified congenital malformation syndromes affecting multiple systems			NA	NA	X	X
Q89.7, Q89.8, Q90.0, Q90.1, Q90.2, Q90.9 Chromosomal abnormalities, not elsewhere classified or Down Syndrome			NA	NA	X	X
Q91.0, Q91.1, Q91.2, Q91.3, Q91.4, Q91.5, Q91.6, Q91.7 Trisomy 18 and Trisomy 13			NA	NA	X	X
Cerebral Degenerations Manifested in Childhood			**X**	**X**		**X**
330.0, 330.1, 330.2, 330.3, 330.8, 330.9 Cerebral degenerations usually manifest in childhood			X	X		NA
G31.81 Alpers disease			NA	NA		X
Cerebral Palsy			**X**	**X**		
343.0, 343.1, 343.2, 343.3, 343.4, 343.8, 343.9, 333.71 Infantile cerebral palsy			X	X		NA
G80.0, G80.1, G80.2, G80.3, G80.4, G80.8, G80.9 Cerebral palsy			NA	NA	X	X
Pervasive and Specific Developmental Disorders	**X**	**X**	**X**	**X**	**X**	**X**
299.0, 299.00, 299.01, 299.1, 299.11, 299.8, 299.80, 288.81, 299.9, 299.90, 299.91 Autism spectrum disorder					X	NA
299.9-299.999 Autism spectrum disorder	X	X	X	X		NA
F81.9, F82 Other Developmental Delays			NA	NA	X	
F84.2 Rett's syndrome			NA	NA		X
F84.0, F84.3, F84.5 Phobic anxiety, Reaction to Severe Stress, or Somatoform disorder	X	X	NA	NA	X	X
F84.1 Other Anxiety Disorders	X	X	NA	NA		
F84.8, F84.9 Other pervasive DD, pervasive DD, unspecified	X	X	NA	NA	X	X
F88, F89 Other Developmental Delays			NA	NA	X	X

Table A-2 (*continued*)						
Code Range	Most Commonly Cited Sources for ID/DD Codes				Federal Agency Definitions	
	Lin 2013	Lunsky 2013	McDermott 2018	Mitra 2015	Definition #1	Definition #2
Learning Disability					**X**	
315, 315.01, 315.02, 315.09, 315.1, 315.2, 315.31, 315.32, 315.34, 315.35, 315.39, 315.4					X	NA
F80.0, F80.1, F80.2, F80.4, F80.81, F80.82, F80.89, F80.9, F81.0, F81.2, F81.81, F81.89, F81.9, F82,			NA	NA	X	
H93.25, R48.0 Central auditory processing disorder or Dyslexia and alexia			NA	NA	X	
Congenital Malformations of the Nervous System	**X**	**X**	**X**		**X**	**X**
Q87.89 Other specified congenital malformation syndromes, not elsewhere classified			NA	NA	X	X
Q89.7 Multiple congenital malformations, not elsewhere classified			NA	NA	X	X
Q89.8 Other specified congenital malformations			NA	NA	X	X
Spina Bifida and Other Congenital Anomalies of the Nervous System	**X**				**X**	
G90.1 Disorders of autonomic nervous system	X		NA	NA	X	
Q000, Q001, Q002 Anencephaly and similar malformations			NA	NA	X	
Q010, Q011, Q012, Q018, Q019 Encephalocele			NA	NA	X	
Q02 Microcephaly			NA	NA	X	
Q030, Q031, Q038, Q039 Congenital hydrocephalus			NA	NA	X	
Q040, Q041, Q042, Q043, Q044, Q045, Q046, Q048, Q049 Other congenital malformations of brain			NA	NA	X	
Q050, Q051, Q053, Q054, Q056, Q057, Q058, Q059 Spina bifida			NA	NA	X	
Q060, Q061, Q062, Q063, Q064, Q068, Q069 Other congenital malformations of spinal cord			NA	NA	X	
Q0700, Q0701, Q0702, Q0703, Q078, Q079 Other congenital malformations of nervous system			NA	NA	X	
Other Congenital Malformations and Chromosomal Anomalies	**X**	**X**	**X**	**X**	**X**	**X**
277.2 Lesch Nyhan Syndrome			X	X		NA
758.5, 758.8, 758.89 (not 758.81), 758.9 Chromosomal anomalies	X	X				NA
759.5 Tuberous sclerosis	X		X	X		NA
759.81, 759.821, 759.827, 759.828, 759.83, 759.874, 759.875, 759.89 † Other and unspecified congenital anomalies (Prader-Wille, Fragile X, Reubinstein Taybi)		X	X	X		NA
Q87.1 Aarrskog, Prader-Wille, de Lange, Seckel, etc	X	X	NA	NA	X	X
Q87.11 Prader-Wille			NA	NA	X	X
Q87.19 Other congenital malformation syndromes predominantly associated with short stature			NA	NA	X	X
Q87.2 Congenital malformation syndromes predominantly involving limbs			NA	NA	X	X
Q87.23 Rubinstein-Taybi syndrome	X	X	NA	NA		

Table A-2 (*continued*)						
Code Range	Most Commonly Cited Sources for ID/DD Codes				Federal Agency Definitions	
	Lin 2013	Lunsky 2013	McDermott 2018	Mitra 2015	Definition #1	Definition #2
Q87.3 Congenital malformation syndromes involving early overgrowth			NA	NA	X	X
Q87.31 Sotos syndrome	X	X	NA	NA		
Q87.8 Other specified congenital malformation syndromes, NEC	X	X	NA	NA		
Q87.81 Alport syndrome					X	X
Q85.1 tuberous sclerosis	X	X	NA	NA		X
Q91.0-Q91.7, Q92.0, Q92.2, Q92.5			NA	NA	X	X
Q92.0, Q92.1, Q92.2, Q92.5, Q92.61, Q92.62, Q92.7, Q92.8, Q92.9 Other trisomies and partial trisomies of autosomes, NEC			NA	NA	X	X
Q93.0, Q93.1, Q93.2, Q93.3, Q93.4, Q93.5, Q93.51, Q93.59, Q93.7, Q93.81, Q93.88, Q93.89, Q93.9 Monosomies and deletions from autosomes, NEC			NA	NA	X	X
Q95.2, Q95.3 Balanced sex/autosomal rearrangement			NA	NA	X	X
Q99.2 Fragile X chromosome			NA	NA	X	X
Down Syndrome	**X**	**X**	**X**	**X**	**X**	**X**
758.0-758.39 Chromosomal anomalies (Down's, Patau's, Edwards' and Autosomal deletion syndromes)	X	X	X	X		NA
Q90.0-Q93.9, except Q92.6, Q97.1, Q99.2, Q99.8 (extra marker chromosomes) Chromosomal abnormalities, NEC	X	X	NA	NA		
Q90.0, Q90.1, Q90.2, Q90.9 Down syndrome					X	X
Fetal alcohol syndrome	**X**	**X**	**X**	**X**	**X**	**X**
760.71, 760.77 Fetus or newborn affected by maternal conditions which may be unrelated to present pregnancy	X	X	X	X		NA
P04.3 Newborn affected by maternal use of alcohol			NA	NA	X	X
Q86.0 Fetal alcohol syndrome (dysmorphic)	X	X	NA	NA	X	X
Q86.1 Fetal hydantoin syndrome	X	X	NA	NA		

Source: RTI International, September 2022.

Notes: For complete citations of articles in this table, see ***Appendix B-1*** and ***B-2***. ICD-9 and ICD-10 codes are grouped under the most approximate corresponding subcategory or subclassifications. Under each header, ICD-9 codes are listed first under the header, begin with a number, and are italicized. ICD-10 codes are listed second and begin with a letter. Where authors reported different individual codes within the same code series, each series is presented exactly as recorded by the author.

† Reflects all Down Syndrome types except extra marker chromosomes

NA = Code is not applicable to the source because the authors did not use the corresponding ICD version. NEC=Not otherwise classified.

Table A-3. Articles in the Literature Scan and Studies Referenced as the Source for Diagnostic Codes Selected to Identify Individuals with ID/DD					
Article in Literature Scan with Reference	**Lin 2013/ Lunsky 2013**	**McDermott 2018**	**Mitra 2015**	**Parish 2015**	**Other Reference**
Number of Articles with Reference	23	11	7	6	22
Akobirshoev 2019†			✓		Akobirshoev 2017
Amir 2022			✓	✓	Akobirshoev 2019
Balogh 2018	✓				
Benevides 2022					
Brown 2021					
Brown 2019	✓				Lin 2014
Brown 2018a	✓				
Brown 2018b	✓				
Brown 2018c	✓				Lin 2015
Calver 2021	✓				
Clements 2020			✓		Mitra 2018, 2019
Durbin 2022	✓				
Durbin 2021	✓				Durbin 2019b
Durbin 2019a	✓				Lin 2014
Durbin 2019b†	✓				
Durbin 2018	✓				Lin 2015
Gomes 2019	✓				
Horner-Johnson 2022		✓			
Kranz 2020		✓			
Lauer 2021		✓			
Lin 2021	✓				
Lindgren 2021		✓			
Lindley 2021					Garfield 2015
Lu 2020		✓			
Lunsky 2022	✓				
Lunsky 2019	✓				
Lunsky 2018	✓				Lin 2014
Mitra 2021					Ouellette-Kuntz 2018
Mitra 2019†			✓	✓	Akobirshoev 2017 Mitra 2018a
Mitra 2018a†					
Mitra 2018b†			✓	✓	
Nishat 2022	✓				Darney 2017 → Lin 2013
Nishat 2021	✓				
Ouellette-Kuntz 2018†	✓				Lin 2014

Table A-3 (*continued*)					
Article in Literature Scan with Reference	**Lin 2013/ Lunsky 2013**	**McDermott 2018**	**Mitra 2015**	**Parish 2015**	**Other Reference**
Parish 2018				✓	
Phillips 2021		✓			Phillips 2019
Phillips 2019†		✓			
Ratnayake 2021					Shooshtari 2011
Rebbe 2021			✓	✓	Chang 2014 Horner-Johnson 2017 Kancherla 2012
Richard 2022		✓			
Rubenstein 2022		✓			
Rubenstein 2020	✓	✓		✓	Brown 2020 → Lin 2013
Stankiewicz 2018	✓				
Straub 2022					Straub 2021
Tarasoff 2020	✓				Darney 2017 → Lin 2013
Whitney 2020					Whitney 2019
Whittingham 2020					Westerinen 2007
Wu 2018			✓		Akobirshoev 2017
Yamaki 2019	✓				
Yamaki 2018†		✓			

Source: RTI International, September 2022
Notes: For complete citations of articles in this table, see ***Appendix Tables B-1*** and ***B-2***.
† Denotes article in the review referenced by other authors as the source of diagnostic codes selected to identify ID/DD.
→ An arrow pointing right indicates that the article to its right is the origin of the diagnostic codes cited by the article to its left and most recently, the article in the scan.

Table A-4. Articles in Literature Scan with No Reference for the Source for Selection of Diagnosis Codes to Identify Individuals with ID/DD		
Akobirshoev 2020	McDermott 2018†	Straub 2021†
Bathje 2021	Mitra 2018a†	Walker 2021
Brown 2021	Reichard 2019	Zandam 2022
Cyrus 2019	Roux 2022	
Koyama 2022	Rubenstein 2021	

Source: RTI International. September 2022
Notes: For complete citations of articles in this table, see ***Appendix B-1***.
† Denotes article in the review referenced by other authors as the source of diagnostic codes selected to identify ID/DD.

APPENDIX B.1: REFERENCE LIST: ARTICLES INCLUDED IN LITERATURE SCAN

Akobirshoev, I., Mitra, M., Parish, S.L., Valentine, A., & Simas, T. (2020). Racial and ethnic disparities in birth outcomes and labor and delivery charges among Massachusetts women with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 58(2), 126-138. doi:10.1352/1934-9556-58.2.126.

Akobirshoev, I., Mitra, M., Parish, S.L., Moore Simas, T.A., Dembo, R., & Ncube, C.N. (2019). Racial and ethnic disparities in birth outcomes and labour and delivery-related charges among women with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 63(4), 313-326. doi:10.1111/jir.12577.

Amir, N., Mitra, M., Leung, K., & Moore Simas, T.A. (2022). Complications following hysterectomy in women with intellectual and developmental disabilities. *Disability and Health Journal*, 15(1), 101213. doi:10.1016/j.dhjo.2021.101213.

Balogh, R., Lin, E., Dobranowski, K., Selick, A., Wilton, A.S., & Lunsky, Y. (2018). All-cause, 30-day readmissions among persons with intellectual and developmental disabilities and mental illness. *Psychiatric Services*, 69(3), 353-357. doi:10.1176/appi.ps.201600534.

Bathje, M., Conrad, S., Medick, M., Ross, M., & Fogg, L. (2021). Differences in hospital-based care for patients with intellectual and developmental disabilities. *American Journal for Occupational Therapy*, 75(3). doi:10.5014/ajot.2021.046508.

Benevides, T.W., Tao, S., Becker, A., Verstreate, K., & Shea, L. (2022). Occupational therapy service delivery among Medicaid-enrolled children and adults on the autism spectrum and with other intellectual disabilities. *American Journal for Occupational Therapy*, 76(1). doi:10.5014/ajot.2022.049202.

Brown, H.K., Ray, J.G., Chen, S., Guttmann, A., Havercamp, S.M., Parish, S., Vigod, S.N, Tarasoff, L.A., & Lunsky, Y. (2021). Association of preexisting disability with severe maternal morbidity or mortality in Ontario, Canada. *Journal of the American Medical Association*, 4(2), e2034993. doi:10.1001/jamanetworkopen.2020.34993.

Brown, H.K., Cobigo, V., Lunsky, Y., & Vigod, S. (2019). Reproductive health in women with intellectual and developmental disabilities in Ontario: Implications for policy and practice. *Healthcare Quarterly*, 21(4), 6-9. doi:10.12927/hcq.2019.25748. PMID: 30946647.

Brown, H.K., Kirkham, Y.A., Lunsky, Y., Cobigo, V., & Vigod, S.N. (2018a). Contraceptive provision to postpartum women with intellectual and developmental disabilities: A population-based cohort study. *Perspectives on Sexual and Reproductive Health*, 50(3), 93-99. doi:10.1363/psrh.12060.

Brown, H.K., Potvin, L.A., Lunsky, Y., & Vigod, S.N. (2018b). Maternal intellectual or developmental disability and newborn discharge to protective services. *Pediatrics*, 142(6). doi:10.1542/peds.2018-1416.

Brown, H.K., Ray, J.G., Liu, N., Lunsky, Y., & Vigod, S.N. (2018c). Rapid repeat pregnancy among women with intellectual and developmental disabilities: A population-based cohort study. *Canadian Medical Association Journal*, 190(32), E949-e956. doi:10.1503/cmaj.170932.

Calver, J., Balogh, R., & Rudoler, D. (2021). Incidence of injury in children and adolescents with intellectual and developmental disability. *Journal of Safety Research*, 77, 56-60. doi:10.1016/j.jsr.2021.02.003.

Clements, K.M., Mitra, M., Zhang, J., & Parish, S.L. (2020). Postpartum health care among women with intellectual and developmental disabilities. *American Journal for Preventative Medicine*, 59(3), 437-444. doi:10.1016/j.amepre.2020.03.011.

Cyrus, A.C., Royer, J., Carroll, D.D., Courtney-Long, E.A., McDermott, S., & Turk, M.A. (2019). Anti-hypertensive medication use and factors related to adherence among adults with intellectual and developmental disabilities. *American Journal for Intellectual and Developmental Disabilities*, 124(3), 248-262. doi:10.1352/1944-7558-124.3.248.

Durbin, A., Balogh, R., Lin, E., Palma, L., Plumptre, L., & Lunsky, Y. (2022). Changes in community and hospital-based health care use during the COVID-19 pandemic for adults with and without intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 66(5), 399-412. doi:10.1111/jir.12929.

Durbin, A., Jung, J.K.H., Chung, H., Lin, E., Balogh, R., & Lunsky, Y. (2021). Health and service use of newcomers and other adults with intellectual and developmental disabilities: A population-based study. *Journal of Applied Research in Intellectual Disabilities*, 34(3), 789-804. doi:10.1111/jar.12856.

Durbin, A., Balogh, R., Lin, E., Wilton, A.S., Selick, A., Dobranowski, K.M., & Lunsky, Y. (2019a). Repeat emergency department visits for individuals with intellectual and developmental disabilities and psychiatric disorders. *American Journal for Intellectual and Developmental Disabilities*, 124(3), 206-219. doi:10.1352/1944-7558-124.3.206.

Durbin, A., Jung, J.K.H., Chung, H., Lin, E., Balogh, R., & Lunsky, Y. (2019b). Prevalence of intellectual and developmental disabilities among first generation adult newcomers, and the health and health service use of this group: A retrospective cohort study. *PLoS One*, 14(6), e0215804. doi:10.1371/journal.pone.0215804.

Durbin, A., Balogh, R., Lin, E., Wilton, A.S., & Lunsky, Y. (2018). Emergency department use: Common presenting issues and continuity of care for individuals with and without intellectual and developmental disabilities. *Journal of Autism and Developmental Disorders*, 48(10), 3542-3550. doi:10.1007/s10803-018-3615-9.

Gomes, T., Khuu, W., Tadrous, M., Vigod, S., Cobigo, V., & Lunsky, Y. (2019). Antipsychotic initiation among adults with intellectual and developmental disabilities in Ontario: A population-based cohort study. *British Medical Journal Open*, 9(7), e028125. doi:10.1136/bmjopen-2018-028125.

Horner-Johnson, W., Lindner, S., Levy, A., Hall, J., Kurth, N., Garcia, E., Frame, A., Phillips, K., Momany, E., Lurie, M., Shin, Y., Lauer, E., Kunte, P., Silverstein, R., Okoro, C., & McDermott, S. (2022). Time trends in emergency department use among adults with intellectual and developmental disabilities. *Disability and Health Journal*, 15(2), 101225. doi:10.1016/j.dhjo.2021.101225.

Koyama, A.K., Koumans, E.H., Sircar, K., Lavery, A., Hsu, J., Ryerson, A.B., & Siegel, D.A. (2022). Severe outcomes, readmission, and length of stay among COVID-19 patients with intellectual and developmental disabilities. *International Journal for Infectious Diseases*, 116, 328-330. doi:10.1016/j.ijid.2022.01.038.

Kranz, A.M., Ross, R., Sorbero, M., Kofner, A., Stein, B.D., & Dick, A.W. (2020). Impact of a Medicaid policy on preventive oral health services for children with intellectual disabilities, developmental disabilities, or both. *Journal for the American Dental Association*, 151(4), 255-264.e253. doi:10.1016/j.adaj.2019.12.001.

Lauer, E., Lindgren, S., Momany, E., Cope, T., Royer, J., Cogan, L., McDermott, S., & Armour, B. (2021). Health service utilization patterns among Medicaid-insured adults with intellectual and developmental disabilities: Implications for access needs in outpatient community-based medical services. *Journal of Ambulatory Care Management*, 44(2), 138-147. doi:10.1097/jac.0000000000000373.

Lin, E., Balogh, R., Chung, H., Dobranowski, K., Durbin, A., Volpe, T., & Lunsky, Y. (2021). Looking across health and healthcare outcomes for people with intellectual and developmental disabilities and psychiatric disorders: Population-based longitudinal study. *British Journal of Psychiatry*, 218(1), 51-57. doi:10.1192/bjp.2020.202.

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APPENDIX B-2: ARTICLES CITED BY AUTHORS IN THE LITERATURE SCAN AS SOURCE FOR ICD-9 AND ICD-10 CODES IDENTIFYING INTELLECTUAL DISABILITIES AND DEVELOPMENTAL DISABILITIES

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