Using Administrative Data to Identify Individuals with Intellectual and Developmental Disabilities: An Exploration in Maine

Methodology Notes

MARCH 2026

Published by Human Services Research Institute & Maine Health Data Organization

Human Services Research Institute

MHDO Maine Health Data Organization

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This paper was supported in part by contract HHSP23320150011911; (IDD Counts Logistics > HSRI), funded by the Administration for Community Living. Its contents are solely the authors' responsibility. They do not necessarily represent the official views of the Administration for Community Living, or the Department of Health and Human Services.

Introduction

The United States spends much more per person on the well-being of people with intellectual and developmental disabilities (IDD[1]) compared to the general population, yet significant preventable health disparities persist.[2] To address these disparities, systems must be able to identify and track experiences and outcomes in this population. Unfortunately, significant limitations remain in the ability to identify people with IDD in both national surveys and administrative data. In response to these challenges, federal efforts to address disparities in the population with IDD have identified data linkages as a priority strategy to better understand prevalence, health care access, outcomes, and associated costs.[3]

Since 2011, Human Services Research Institute (HSRI) has undertaken several projects aimed at addressing gaps in national health surveillance for the IDD population, including efforts to operationalize definitions of intellectual and developmental disability for health monitoring. HSRI currently manages the I/DD Counts initiative, supported by the Administration for Community Living (ACL) and the Centers for Disease Control and Prevention National Center on Birth Defects and Developmental Disabilities (CDC/NCBDDD). HSRI has more than 25 years of experience collecting and reporting outcomes and quality measures for individuals with IDD receiving community-based supports and services through the National Core Indicators – Intellectual and Developmental Disabilities (NCI-IDD). For NCI-IDD, HSRI works directly with states and maintains a web-based data entry system, analyzes all data collected, and prepares topical data briefs and state-level data reports. Additionally, HSRI has collaborated with the State of Maine's Maine Health Data Organization (MHDO) to build Maine's health data warehouse, which includes an All-Payer Claims Database (APCD) and a Hospital Encounter Database. These administrative databases are important independently but can be linked with other data sources to enhance the ability to understand health system's performance, monitor disease prevalence and prevention, and perform outcomes analyses to inform policy and practice.

To support addressed gaps in the health surveillance of the IDD population, HSRI conducted a feasibility study in spring 2023 using two Maine health care data systems maintained by MHDO: the APCD and the Hospital Encounter Database. Using MHDO's de-identified person-index to link these data systems, the study evaluated whether individuals with IDD could be reliably identified within these administrative datasets. This work aimed to enhance data-driven insights into the IDD population's health services utilization and outcomes, providing a foundation for targeted improvements in health care access and quality. A person-level IDD status flag (see Appendix C) was created based on a literature review that explored approaches for identifying

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[1] The acronym IDD is used when referring to people with intellectual and/or developmental disabilities. The acronym I/DD is used for the ACL-funded project *I/DD Counts*.

[2] Krahn, G. (2019). A call for better data on prevalence and health surveillance of people with intellectual and developmental disabilities*. Intellectual and Developmental Disabilities, 57*(5), 357–375.

[3] Office of the Assistant Secretary for Planning and Evaluation. (2022). *Improving data infrastructure for patient-centered outcomes research for people with intellectual and developmental disabilities.* https://aspe.hhs.gov/reports/improving-data-infrastructure-pcor-people-iddd

people with IDD, enhancing the person-index characteristics describing an individual. This IDD status flag enables:

- Demographic analysis of the IDD population in Maine
- Analyses of health service utilization and outcomes by IDD status
- Opportunities for data linkages with other administrative data sources, such as disease registries and vital statistics records

HSRI, based in Cambridge, Mass., is a 501(c)(3) nonprofit organization founded in 1976. For 50 years, HSRI has pursued its mission to improve systems that change lives by conducting robust, collaborative, inclusive, and participatory research that responds to population-level needs. HSRI has demonstrated expertise in advancing population health surveillance for individuals IDD and in managing and analyzing state-level administrative datasets.

The analysis, presented as a poster at the Academy Health Annual Research Meeting in June 2023, provides a framework for leveraging administrative data to identify and address disparities in the IDD population. The methodology used to create the IDD status flag is described below.

Data Sources

The two data sources used for this analysis are the MHDO APCD and the MHDO Hospital Encounter Database for the time period January 1, 2018 – December 31, 2022. MHDO's rule 90-590 Chapter 243, *Uniform Reporting System for Health Care Claims Data Sets*, governs the requirements and standards for data submission to the MHDO APCD, including which organizations must report and the content, format, method, and time frame for submissions. Similarly, MHDO's rule 90-590 *Chapter 241, Uniform Reporting System for Hospital Inpatient Data Sets and Hospital Outpatient Data Sets*, governs the requirements and standards for data submission to the MHDO Hospital Encounters database. Access to MHDO data was authorized per the terms and conditions of MHDO's rule 90-590 *Chapter 120, Release of Data to the Public*.

Over 50 commercial payors (including Medicare Advantage plans) and MaineCare (the State's Medicaid/CHIP program) submit their claims data (referred to as raw data) to MHDO. The data elements submitted to the MHDO APCD by payors aligns with the information populated in standardized claims forms (UB-04 and the CMS-1500) used by hospitals and other health care providers. The data elements submitted to the MHDO Hospital Encounter Database by hospitals are the same as those provided in the most current National Uniform Billing Data Element Specifications as developed by the National Uniform Billing Committee.

The MHDO APCD contains health care eligibility and medical, pharmacy, and dental claims records from commercial and public payors. The claims reported to MHDO include all MaineCare and Medicare (both Original Medicare and Medicare Advantage) members, approximately 84% of the fully insured individual and employer-sponsored plans, and approximately 26% of the self-funded employer-sponsored plans (referred to as Commercial). A portion of the self-funded employer-sponsored plans are Employee Retirement Income Security Act of 1974 (ERISA) plans, and due to a United States Supreme Court ruling (*Gobeille v. Liberty Mutual Insurance Company*) in March 2016, they are exempt from submitting data to

state APCDs. However, some of the largest ERISA self-funded plans submit data to MHDO on a voluntary basis. Health plans with less than $2 million in annual premiums are exempt from submitting data to MHDO. MHDO's claims data does not include data for the uninsured.

The MHDO Hospital Encounter Database contains records from all insured and uninsured individuals who received inpatient or outpatient services from hospitals and hospital-owned specialty groups or primary care practices (100% of encounters in those settings). The data captured by this database is not dependent on individual-level insurance coverage; if an individual received a service through one of the hospital systems, that encounter information is captured in this database. In any given year, the database includes almost 60% of Maine's population.

Administrative claims data, such as the claims from the MHDO APCD, are records generated when health care providers submit claims for reimbursement to insurers, including commercial and public payors. Claims data typically includes the following components:

- Patient demographics: Age, gender, location, and insurance coverage
- Provider information: Provider (billing, rendering, attending, operating, prescribing) National Provide Identifier (NPI), classification and specialization, and location
- Service information: Diagnoses, procedures, and prescriptions as captured using a combination of International Classification of Disease (ICD) codes, Current Procedural Terminology (CPT) codes, and/or Healthcare Common Procedure Coding System (HCPCS) codes
- Utilization information: Service dates and visit types, such as inpatient admissions, outpatient visits, and emergency department visits
- Financial information: The amount billed and the amount allowed for a service or procedure, and the portion of the allowed amount that is the patient responsibility versus the payor responsibility
- Enrollment information: Insurance eligibility and coverage history

Similarly, administrative hospital encounter data, such as the data within the MHDO Hospital Encounter Database, are medical records collected by hospitals for internal use, state reporting, and research. These datasets contain many of the same data elements as administrative claims data (other than financial information) but are limited to care among hospital-affiliated providers, capturing inpatient stays, emergency department visits, outpatient hospital services, and physician practices. Unlike APCD data, hospital encounter data contains data from both insured and uninsured patients.

While claims and hospital encounter data can provide insights into health care utilization, neither type includes information about direct health outcomes. They can indicate how often a service is used or how many times a prescription is filled, but they lack clinical measures such as diagnostic test results or blood pressure measurements. However, proxy measures can sometimes be used to infer health outcomes.

To gain a more comprehensive view, claims and hospital encounter data can be linked using MHDO's de-identified person-index key (or Person ID) —provided that accurate patient identifiers are available. This key assigns a single set of demographic characteristics to a person

using custom logic to ensure the most accurate submissions are used. Additionally, linking these datasets with other data sources—such as electronic health records, vital statistics records, disease registries including cancer registries, and Census data—can enhance analyses of health care access, quality, and outcomes.

Time Period

The feasibility analysis used MHDO's APCD medical claims and Hospital Encounters records for January 1, 2018 through December 31, 2022 (the most recent data available in spring 2023), using the following criteria:

- **Medical claims** for 2018 through 2022 were selected based on the *service start date* on the claim line for hospital outpatient encounters and related professional claims and based on the *admission date* for hospital inpatient claims.
- **Hospital encounter records** for 2018 through 2022 were selected based on the *statement covers period through date*.

Data Preparation

Claims data and hospital encounters data submitted to MHDO undergo data processing, including to identify and remove fully reversed claims and incomplete, incorrect, or duplicate data. This process is designed to improve the accuracy and reliability of the data. The processing steps undertaken on the submitted data is summarized in Appendix A.

Appendix B contains the list of medical claims, hospital encounters, and person-index elements used to develop the analytic dataset.

Methodology

There are a variety of methods available to identify populations for health surveillance research. A list of International Classification of Diseases-Tenth Revision (ICD-10-CM) diagnosis codes related to IDD diagnoses were derived from the Clinical Classifications Software Refined (CCSR) tool for ICD-10-CM diagnoses, developed by the Health Care Utilization Project (HCUP) under the Agency for Healthcare Research and Quality (AHRQ)[4], and the Centers for Medicare & Medicaid Services' Chronic Conditions Data Warehouse (CCW)[5]. Table C.1 in Appendix C contains the list of IDD diagnosis inclusion codes.

[4] https://hcup-us.ahrq.gov/toolssoftware/ccsr/ccs_refined.jsp
[5] https://www2.ccwdata.org/web/guest/condition-categories

Procedure and Diagnosis History

To obtain the procedure and diagnosis history for all individuals (de-identified) in the MHDO APCD and MHDO Hospital Encounter Database, we created separate datasets with the following elements from each source:

- **Medical claims** – Claim ID, Person ID, billing provider NPI, servicing provider NPI, payor, service dates, CPT/HCPCS codes, ICD-10-CM diagnosis codes, and ICD-10-PCS procedure codes
- **Hospital inpatient records** – Encounter ID, Person ID, hospital submitter, payor, service dates, ICD-10-PCS procedure codes, and ICD-10-CM diagnosis codes
- **Hospital outpatient records** – Encounter ID, Person ID, hospital submitter, payor, service dates, CPT/HCPCS codes, and ICD-10-CM diagnosis codes

These datasets were then combined into a deduplicated dataset containing all services, procedures, and associated diagnoses for individuals with an available Person ID. All individuals with available health care records in the 2018-2022 MHDO APCD and MHDO Hospital Encounter Database were included in the analytic dataset.

IDD Status

Diagnosis codes were used to identify people with IDD; if an IDD diagnosis was not coded on the claim and a person had IDD, they would not be captured in this analysis, resulting in an undercount of the population. In future analyses, it may be beneficial to broaden the approach to identifying people with IDD by reviewing IDD service codes in addition to reviewing diagnosis codes, or by obtaining a list of Home and Community Based Services (HCBS) recipients from the state.

If a person had at least one medical claim or hospital inpatient or hospital outpatient encounter record with an IDD principal or secondary diagnosis, their person-level IDD status flag was set to 1. This method of identification assumes that during the five-year period of interest, people with IDD would have accessed at least one health care service, and that an IDD diagnosis would be present as a primary or secondary diagnosis on the health care encounter. Subcategory IDD status flags were also created to distinguish people with diagnoses related to intellectual disabilities, autism, pervasive developmental disorder, or learning disabilities. Subcategories were not mutually exclusive; if a person had an intellectual disability and an autism diagnosis, they were included in both subcategories. Table C.2 in Appendix C contains the list of IDD subcategories and their corresponding inclusion codes.

Payors

Because individuals may change insurance coverage over time, we created a person-level flag to identify all payors that covered each person at any point during the five-year period. The payors categories were:

- Commercial only
- Medicaid only
- Medicare Fee-for-Service (FFS) only

- Medicare Advantage only
- Other payor only (TRICARE/USVA, Charity/Uncompensated Care, Self-Pay, Workers Compensation, Other, Unknown/Undetermined)
- Multiple payors (Commercial, Medicaid, Medicare FFS, Medicare Advantage, or Other)

Demographic Characteristics

Using data from MHDO's de-identified person-index, individuals' age, gender, ethnicity, and race were determined. Only Maine residents, as determined by home zip code, were reported in results.

Future Directions

This resource is intended to serve as a technical guide for others seeking to explore the use of APCDs and other health care datasets with primary and secondary diagnosis codes to study prevalence and health care use among people with IDD. Different data sources often use different methods to determine whether individuals have IDD, resulting in varying estimates of prevalence and inconsistent findings on health inequities. To determine accurate estimates, there is a need for greater transparency in the methods used to define IDD. This report provides a framework for promoting transparency and facilitating comparisons between data sources using different definitions of IDD.

This work is closely connected to the goals of the ACL-funded **I/DD Counts** project. The I/DD Counts project has developed a roadmap for better IDD data, which outlines the fundamental importance of strengthening administrative data by developing and sharing standard definitions of IDD in available data. This standardization is key to harmonizing and subsequently linking data from different sources to more comprehensively assess health inequities for people with IDD.

Appendices

Appendix A: MHDO Data Intake and Processing

The MHDO APCD and Hospital Encounters data are submitted to MHDO per the requirements in 90-590 Chapter 243, *Uniform Reporting System for Health Care Claims Data Sets* and *Chapter 241, Uniform Reporting System for Hospital Inpatient Data Sets and Hospital Outpatient Data Sets*. The claims data and hospital encounters data submitted to MHDO undergoes data scrubbing, which is the process of fixing errors in a database by identifying and removing incomplete, incorrect, or duplicate data. It also involves standardizing formats and updating outdated information. This process is designed to improve the accuracy and reliability of the data.

After passing data intake validations, the data are ingested into the MHDO Data Warehouse, where they are processed, enhanced with value-add fields, and then subjected to an additional round of internal quality checks. The table below outlines these steps.

TABLE A.1. MHDO APCD AND HOSPITAL ENCOUNTER DATA PROCESSING STEPS IN THE DATA WAREHOUSE

Step	Task	Description
1	**Receive Raw Data Files**	Raw data are received from the source, data are loaded into the MHDO Data Warehouse.
2	**Enhance Data**	Process the data files by running queries and batch jobs to load the data into the appropriate file formats and bring the files into output tables. Specifications for enhancements are documented in the Business Rules.
3	**Conduct Internal Quality Control (QC)**	Execute QC based on dataset. This may include: Running variable checks to ensure key variables are used in analysis; checking output tables to ensure the correct relationships are established and information is appearing correctly; comparing current estimates to previous estimates; performing outlier analysis; reviewing data for new procedures or methodological changes; reviewing any open issues identified in past processing iterations. Document progress and results as needed.
4	**Investigate and Resolve Issues**	Investigate and resolve critical issues identified during the internal QC process.
5	**Rerun Data (if necessary)**	If data issues are identified, rerun the data and conduct internal QC.
7	**Investigate and Resolve Issues**	Investigate and resolve critical issues identified during the external QC process, as discussed with the MHDO Compliance Officer and Executive Director.
8	**Accept or Reject Data**	MHDO accepts or rejects the data deliverable based on the testing results. When accepted, the data are released.
9	**Metadata and Release Documentation**	Metadata and associated release documentation is updated with changes or data quality concerns and released with data.

Appendix B: MHDO Data Elements Used in the Analysis

This appendix includes four lists of MHDO data elements used for this analysis, one for the MHDO APCD (Table B.1), one for MHDO Hospital Inpatient Encounters (Table B.2), one for MHDO Hospital Outpatient Encounters (Table B.3), and one for the MHDO Person- Index (Table B.4).

TABLE B.1. MHDO APCD MEDICAL CLAIMS

Data Element	Data Element Name	Transformation Type
MC002_PAYER	MHDO Payer ID	As Submitted
MC016_PATZIP	Member ZIP Code	As Submitted
MC018_ADMDAT	Admission Date	As Submitted
MC055_CPT	Procedure Code	As Submitted
MC056_MOD1	Procedure Modifier 1	As Submitted
MC057_MOD2	Procedure Modifier 2	As Submitted
MC059_FDATE	Date of Service From	As Submitted
MC060_LDATE	Date of Service Through	As Submitted
MC069_DISDAT	Discharge Date	As Submitted
MC200_PRINDGNS	Principal Diagnosis	As Submitted
MC254_OTHDX1	Other Diagnosis-1	As Submitted
MC256_OTHDX2	Other Diagnosis-2	As Submitted
MC258_OTHDX3	Other Diagnosis-3	As Submitted
MC260_OTHDX4	Other Diagnosis-4	As Submitted
MC262_OTHDX5	Other Diagnosis-5	As Submitted
MC264_OTHDX6	Other Diagnosis-6	As Submitted
MC266_OTHDX7	Other Diagnosis-7	As Submitted
MC268_OTHDX8	Other Diagnosis-8	As Submitted
MC270_OTHDX9	Other Diagnosis-9	As Submitted
MC272_OTHDX10	Other Diagnosis-10	As Submitted
MC274_OTHDX11	Other Diagnosis-11	As Submitted
MC276_OTHDX12	Other Diagnosis-12	As Submitted
MC278_OTHDX13	Other Diagnosis-13	As Submitted
MC280_OTHDX14	Other Diagnosis-14	As Submitted
MC282_OTHDX15	Other Diagnosis-15	As Submitted
MC284_OTHDX16	Other Diagnosis-16	As Submitted
MC286_OTHDX17	Other Diagnosis-17	As Submitted
MC288_OTHDX18	Other Diagnosis-18	As Submitted
MC290_OTHDX19	Other Diagnosis-19	As Submitted
MC292_OTHDX20	Other Diagnosis-20	As Submitted
MC294_OTHDX21	Other Diagnosis-21	As Submitted
MC296_OTHDX22	Other Diagnosis-22	As Submitted
MC298_OTHDX23	Other Diagnosis-23	As Submitted
MC300_OTHDX24	Other Diagnosis-24	As Submitted
MC302_PRNPRCDRCD	Principal Procedure Code	As Submitted
MC303_OTHPRCDRCD1	Other Procedure Code-1	As Submitted
MC304_OTHPRCDRCD2	Other Procedure Code-2	As Submitted
MC305_OTHPRCDRCD3	Other Procedure Code-3	As Submitted
MC306_OTHPRCDRCD4	Other Procedure Code-4	As Submitted
MC307_OTHPRCDRCD5	Other Procedure Code-5	As Submitted
MC308_OTHPRCDRCD6	Other Procedure Code-6	As Submitted

Data Element	Data Element Name	Transformation Type
MC309_OTHPRCDRCD7	Other Procedure Code-7	As Submitted
MC310_OTHPRCDRCD8	Other Procedure Code-8	As Submitted
MC311_OTHPRCDRCD9	Other Procedure Code-9	As Submitted
MC312_OTHPRCDRCD10	Other Procedure Code-10	As Submitted
MC313_OTHPRCDRCD11	Other Procedure Code-11	As Submitted
MC314_OTHPRCDRCD12	Other Procedure Code-12	As Submitted
MC315_OTHPRCDRCD13	Other Procedure Code-13	As Submitted
MC316_OTHPRCDRCD14	Other Procedure Code-14	As Submitted
MC317_OTHPRCDRCD15	Other Procedure Code-15	As Submitted
MC318_OTHPRCDRCD16	Other Procedure Code-16	As Submitted
MC319_OTHPRCDRCD17	Other Procedure Code-17	As Submitted
MC320_OTHPRCDRCD18	Other Procedure Code-18	As Submitted
MC321_OTHPRCDRCD19	Other Procedure Code-19	As Submitted
MC322_OTHPRCDRCD20	Other Procedure Code-20	As Submitted
MC323_OTHPRCDRCD21	Other Procedure Code-21	As Submitted
MC324_OTHPRCDRCD22	Other Procedure Code-22	As Submitted
MC325_OTHPRCDRCD23	Other Procedure Code-23	As Submitted
MC326_OTHPRCDRCD24	Other Procedure Code-24	As Submitted
MC902_IDN	Record ID#	Derived
MC907_MHDO_CLAIM	MHDO assigned replacement for payer's claim ID	Derived
MC913_MHDO_PRODUCT	Standardized Insurance Type/Product Code	Derived
MC950_SERVICING_NPI	National Provider ID - Servicing Provider	Derived
MC967_Billing_Provider_NPI	National Provider ID - Billing Provider	Derived
MC976_Person_ID	Deidentified MHDO-assigned replacement Person ID	Derived

TABLE B.2. MHDO HOSPITAL INPATIENT ENCOUNTERS

Data Element	Data Element Name	Transformation Type
IPMB01_IDN	Unique Record Identifier	Derived
IP0102_SubmitterEIN	MHDO-Assigned Hospital ID	As Submitted
IP2011_AdmissionStartCareDate	Admission/start of care date	As Submitted
IP2013_StatementCoversPeriod Through	Statement covers period through	As Submitted
IP7104_PrincipalDiagnosis	Principal Diagnosis	As Submitted
IP7110_PrincipalProcedureCode	Principal Procedure code	As Submitted
IP7111_PrincipalProcedureDate	Principal Procedure date	As Submitted
IP72OPD02_MasterIDN	Unique Record Identifier	Derived
IP7202_SequenceNumber	Sequence number	As Submitted
IP7402_SequenceNumber	Sequence number	As Submitted
IP7204_OtherProcedureCode1	Other Procedure code 1	As Submitted
IP7205_OtherProcedureDate1	Other Procedure date 1	As Submitted
IP7206_OtherProcedureCode2	Other Procedure code 2	As Submitted
IP7207_OtherProcedureDate2	Other Procedure date 2	As Submitted
IP7208_OtherProcedureCode3	Other Procedure code 3	As Submitted
IP7209_OtherProcedureDate3	Other Procedure date 3	As Submitted
IP7210_OtherProcedureCode4	Other Procedure code 4	As Submitted
IP7211_OtherProcedureDate4	Other Procedure date 4	As Submitted
IP7212_OtherProcedureCode5	Other Procedure code 5	As Submitted
IP7213_OtherProcedureDate5	Other Procedure date 5	As Submitted
IP7214_OtherProcedureCode6	Other Procedure code 6	As Submitted
IP7215_OtherProcedureDate6	Other Procedure date 6	As Submitted
IP7216_OtherProcedureCode7	Other Procedure code 7	As Submitted

Data Element	Data Element Name	Transformation Type
IP7217_OtherProcedureDate7	Other Procedure date 7	As Submitted
IP7218_OtherProcedureCode8	Other Procedure code 8	As Submitted
IP7219_OtherProcedureDate8	Other Procedure date 8	As Submitted
IP7404_OtherDiagnosisCode1	Other Diagnosis code 1	As Submitted
IP7406_OtherDiagnosisCode2	Other Diagnosis code 2	As Submitted
IP7408_OtherDiagnosisCode3	Other Diagnosis code 3	As Submitted
IP7410_OtherDiagnosisCode4	Other Diagnosis code 4	As Submitted
IP7412_OtherDiagnosisCode5	Other Diagnosis code 5	As Submitted
IP7414_OtherDiagnosisCode6	Other Diagnosis code 6	As Submitted
IP7416_OtherDiagnosisCode7	Other Diagnosis code 7	As Submitted
IP7418_OtherDiagnosisCode8	Other Diagnosis code 8	As Submitted
IP7420_OtherDiagnosisCode9	Other Diagnosis code 9	As Submitted
IP7422_OtherDiagnosisCode10	Other Diagnosis code 10	As Submitted
IP7424_OtherDiagnosisCode11	Other Diagnosis code 11	As Submitted
IP7426_OtherDiagnosisCode12	Other Diagnosis code 12	As Submitted
IPML20_ZIP_5	Patient ZIP code	As Submitted
IPMPY20_PAY1	MHDO-assigned payer classification code 1	As Submitted
IPMB10_Person_ID	MHDO De-Identified Replacement Person ID	Derived

TABLE B.3. MHDO HOSPITAL OUTPATIENT ENCOUNTERS

Data Element	Data Element Name	Transformation Type
OPMB01_IDN	Unique Record Identifier	Derived
OP0102_SubmitterEIN	MHDO-Assigned Hospital ID	As Submitted
OP2011_AdmissionStartCareDate	Admission/start of care date	As Submitted
OP2013_StatementCoversPeriod Through	Statement covers period through	As Submitted
OP6105_HCPCSCode	HCPCS Procedure code	As Submitted
OP6106_HCPCSCode_Mod1	Modifier 1 (HCPCS & CPT-4) 1	As Submitted
OP6107_HCPCSCode_Mod2	Modifier 2 (HCPCS & CPT-4) 1	As Submitted
OP7104_PrincipalDiagnosis	Principal Diagnosis	As Submitted
OP7202_SequenceNumber	Sequence number	As Submitted
OP7402_SequenceNumber	Sequence number	As Submitted
OP7404_OtherDiagnosisCode1	Other Diagnosis code 1	As Submitted
OP7406_OtherDiagnosisCode2	Other Diagnosis code 2	As Submitted
OP7408_OtherDiagnosisCode3	Other Diagnosis code 3	As Submitted
OP7410_OtherDiagnosisCode4	Other Diagnosis code 4	As Submitted
OP7412_OtherDiagnosisCode5	Other Diagnosis code 5	As Submitted
OP7414_OtherDiagnosisCode6	Other Diagnosis code 6	As Submitted
OP7416_OtherDiagnosisCode7	Other Diagnosis code 7	As Submitted
OP7418_OtherDiagnosisCode8	Other Diagnosis code 8	As Submitted
OP7420_OtherDiagnosisCode9	Other Diagnosis code 9	As Submitted
OP7422_OtherDiagnosisCode10	Other Diagnosis code 10	As Submitted
OP7424_OtherDiagnosisCode11	Other Diagnosis code 11	As Submitted
OP7426_OtherDiagnosisCode12	Other Diagnosis code 12	As Submitted
OPML20_ZIP_5	Patient ZIP code	As Submitted
OPMPY20_PAY1	MHDO-assigned payer classification code 1	As Submitted
OPMB10_Person_ID	MHDO Deidentified Replacement Person ID	Derived

TABLE B.4. MHDO PERSON-INDEX

Data Element	Data Element Name	Transformation Type
DOB	Date of birth	Derived
First_Sex	Most common submitted sex across Data Warehouse (DW) data sources in the earliest available 6-month period	Derived
AI_AN	American Indian/Alaskan Native race, DW derived composite assignment	Derived
Asian	Asian race, DW derived composite assignment	Derived
Black	Black or African American race, DW derived composite assignment	Derived
NH_PI	Native Hawaiian/Pacific Islander race, DW derived composite assignment	Derived
White	White or Caucasian race, DW derived composite assignment	Derived
Race_Other	Other Race, DW derived composite assignment	Derived
Race_Unknown	Race is not otherwise known	Derived
Hispanic	Hispanic ethnicity, DW derived composite assignment	Derived
Non_Hispanic	Non-Hispanic ethnicity, DW derived composite assignment	Derived

Appendix C: ICD-10-CM Codes for IDD Diagnosis Identification

Table C.1 lists the ICD-10-CM codes used to identify a person with an IDD diagnosis in the MHDO APCD or Hospital Encounter Database. Table C.2 is a crosswalk of the ICD-10-CM codes and how they were categorized into specific IDD subgroups for reporting.

TABLE C.1. IDD DIAGNOSIS CODES

ICD-10-CM Code	ICD-10-CM Code Description
E71520	Childhood cerebral X-linked adrenoleukodystrophy
E7523	Krabbe disease
E7525	Metachromatic leukodystrophy
E7871	Barth syndrome
E7872	Smith-Lemli-Opitz syndrome
E791	Lesch-Nyhan syndrome
F70	Mild intellectual disabilities
F71	Moderate intellectual disabilities
F72	Severe intellectual disabilities
F73	Profound intellectual disabilities
F78	Other intellectual disabilities
F78A1	SYNGAP1-related intellectual disability
F78A9	Other genetic related intellectual disability
F79	Unspecified intellectual disabilities
F800	Phonological disorder
F801	Expressive language disorder
F802	Mixed receptive-expressive language disorder
F8082	Social pragmatic communication disorder
F8089	Other developmental disorders of speech and language
F82	Specific developmental disorder of motor function
F840	Autistic disorder
F842	Rett's syndrome
F843	Other childhood disintegrative disorder
F845	Asperger's syndrome
F848	Other pervasive developmental disorders
F849	Pervasive developmental disorder, unspecified
F88	Other disorders of psychological development
F89	Unspecified disorder of psychological development
G3181	Alpers disease
G800	Spastic quadriplegic cerebral palsy
G801	Spastic diplegic cerebral palsy
G802	Spastic hemiplegic cerebral palsy
G803	Athetoid cerebral palsy
G804	Ataxic cerebral palsy
G808	Other cerebral palsy
G809	Cerebral palsy, unspecified
G901	Familial dysautonomia [Riley-Day]
H9325	Central auditory processing disorder

ICD-10-CM Code	ICD-10-CM Code Description
P043	Newborn affected by maternal use of alcohol
Q000	Anencephaly
Q001	Craniorachischisis
Q002	Iniencephaly
Q010	Frontal encephalocele
Q011	Nasofrontal encephalocele
Q012	Occipital encephalocele
Q018	Encephalocele of other sites
Q019	Encephalocele, unspecified
Q02	Microcephaly
Q030	Malformations of aqueduct of Sylvius
Q031	Atresia of foramina of Magendie and Luschka
Q038	Other congenital hydrocephalus
Q039	Congenital hydrocephalus, unspecified
Q040	Congenital malformations of corpus callosum
Q041	Arhinencephaly
Q042	Holoprosencephaly
Q043	Other reduction deformities of brain
Q044	Septo-optic dysplasia of brain
Q045	Megalencephaly
Q046	Congenital cerebral cysts
Q048	Other specified congenital malformations of brain
Q049	Congenital malformation of brain, unspecified
Q050	Cervical spina bifida with hydrocephalus
Q051	Thoracic spina bifida with hydrocephalus
Q052	Lumbar spina bifida with hydrocephalus
Q053	Sacral spina bifida with hydrocephalus
Q054	Unspecified spina bifida with hydrocephalus
Q055	Cervical spina bifida without hydrocephalus
Q056	Thoracic spina bifida without hydrocephalus
Q057	Lumbar spina bifida without hydrocephalus
Q058	Sacral spina bifida without hydrocephalus
Q059	Spina bifida, unspecified
Q060	Amyelia
Q061	Hypoplasia and dysplasia of spinal cord
Q062	Diastematomyelia
Q063	Other congenital cauda equina malformations
Q064	Hydromyelia
Q068	Other specified congenital malformations of spinal cord
Q069	Congenital malformation of spinal cord, unspecified
Q0700	Arnold-Chiari syndrome without spina bifida or hydrocephalus
Q0701	Arnold-Chiari syndrome with spina bifida
Q0702	Arnold-Chiari syndrome with hydrocephalus
Q0703	Arnold-Chiari syndrome with spina bifida and hydrocephalus
Q078	Other specified congenital malformations of nervous system
Q079	Congenital malformation of nervous system, unspecified
Q851	Tuberous sclerosis
Q860	Fetal alcohol syndrome (dysmorphic)
Q861	Fetal hydantoin syndrome

ICD-10-CM Code	ICD-10-CM Code Description
Q871	Congenital malformation syndromes predominantly associated with short stature
Q8711	Prader-Willi syndrome
Q8719	Other congenital malformation syndromes predominantly associated with short stature
Q872	Congenital malformation syndromes predominantly involving limbs
Q873	Congenital malformation syndromes involving early overgrowth
Q875	Other congenital malformation syndromes with other skeletal changes
Q8781	Alport syndrome
Q8789	Other specified congenital malformation syndromes, not elsewhere classified
Q897	Multiple congenital malformations, not elsewhere classified
Q898	Other specified congenital malformations
Q900	Trisomy 21, nonmosaicism (meiotic nondisjunction)
Q901	Trisomy 21, mosaicism (mitotic nondisjunction)
Q902	Trisomy 21, translocation
Q909	Down syndrome, unspecified
Q910	Trisomy 18, nonmosaicism (meiotic nondisjunction)
Q911	Trisomy 18, mosaicism (mitotic nondisjunction)
Q912	Trisomy 18, translocation
Q913	Trisomy 18, unspecified
Q914	Trisomy 13, nonmosaicism (meiotic nondisjunction)
Q915	Trisomy 13, mosaicism (mitotic nondisjunction)
Q916	Trisomy 13, translocation
Q917	Trisomy 13, unspecified
Q920	Whole chromosome trisomy, nonmosaicism (meiotic nondisjunction)
Q921	Whole chromosome trisomy, mosaicism (mitotic nondisjunction)
Q922	Partial trisomy
Q925	Duplications with other complex rearrangements
Q9261	Marker chromosomes in normal individual
Q9262	Marker chromosomes in abnormal individual
Q927	Triploidy and polyploidy
Q928	Other specified trisomies and partial trisomies of autosomes
Q929	Trisomy and partial trisomy of autosomes, unspecified
Q930	Whole chromosome monosomy, nonmosaicism (meiotic nondisjunction)
Q931	Whole chromosome monosomy, mosaicism (mitotic nondisjunction)
Q932	Chromosome replaced with ring, dicentric or isochromosome
Q933	Deletion of short arm of chromosome 4
Q934	Deletion of short arm of chromosome 5
Q935	Other deletions of part of a chromosome
Q9351	Angelman syndrome
Q9359	Other deletions of part of a chromosome
Q937	Deletions with other complex rearrangements
Q9381	Velo-cardio-facial syndrome
Q9382	Williams syndrome
Q9388	Other microdeletions
Q9389	Other deletions from the autosomes
Q939	Deletion from autosomes, unspecified
Q952	Balanced autosomal rearrangement in abnormal individual
Q953	Balanced sex/autosomal rearrangement in abnormal individual
Q971	Female with more than three X chromosomes
Q992	Fragile X chromosome

ICD-10-CM Code	ICD-10-CM Code Description
Q998	Other specified chromosome abnormalities

TABLE C.2. IDD DIAGNOSIS CODES BY SUBCATEGORY

ICD-10-CM Code	ICD-10-CM Code Description	Subcategory
F840	Autistic disorder	Autism, Pervasive Developmental Disorder, Aspergers syndrome
F842	Rett's syndrome	Autism, Pervasive Developmental Disorder, Aspergers syndrome
F843	Other childhood disintegrative disorder	Autism, Pervasive Developmental Disorder, Aspergers syndrome
F845	Asperger's syndrome	Autism, Pervasive Developmental Disorder, Aspergers syndrome
F848	Other pervasive developmental disorders	Autism, Pervasive Developmental Disorder, Aspergers syndrome
F849	Pervasive developmental disorder, unspecified	Autism, Pervasive Developmental Disorder, Aspergers syndrome
F88	Other disorders of psychological development	Autism, Pervasive Developmental Disorder, Aspergers syndrome
F89	Unspecified disorder of psychological development	Autism, Pervasive Developmental Disorder, Aspergers syndrome
E7871	Barth syndrome	Intellectual Disabilities
E7872	Smith-Lemli-Opitz syndrome	Intellectual Disabilities
E791	Lesch-Nyhan syndrome	Intellectual Disabilities
F70	Mild intellectual disabilities	Intellectual Disabilities
F71	Moderate intellectual disabilities	Intellectual Disabilities
F72	Severe intellectual disabilities	Intellectual Disabilities
F73	Profound intellectual disabilities	Intellectual Disabilities
F78	Other intellectual disabilities	Intellectual Disabilities
F78A1	SYNGAP1-related intellectual disability	Intellectual Disabilities
F78A9	Other genetic related intellectual disability	Intellectual Disabilities
F79	Unspecified intellectual disabilities	Intellectual Disabilities
F800	Phonological disorder	Learning Disability
F801	Expressive language disorder	Learning Disability
F802	Mixed receptive-expressive language disorder	Learning Disability
F8082	Social pragmatic communication disorder	Learning Disability
F8089	Other developmental disorders of speech and language	Learning Disability
F82	Specific developmental disorder of motor function	Learning Disability
H9325	Central auditory processing disorder	Learning Disability