Opportunities to Identify Individuals with Intellectual and Developmental Disabilities in Maine Using Administrative Data

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Human Services Research Institute (HSRI)

MHDO Maine Health Data Organization

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Objective

This analysis demonstrates the ability to identify people with intellectual and developmental disabilities (IDD) in two health care data systems in Maine, the Maine Health Data Organization's All-Payer Claims Database (MHDO APCD) and MHDO's Hospital Encounter Database, by using MHDO's de-identified person-index. A person-level IDD status flag was created, enhancing the person-index characteristics describing an individual and allowing us to describe the demographics of the identified IDD population in Maine. This IDD status flag can be used to disaggregate health services for individuals with IDD and monitor their health outcomes.

Background

The U.S. spends much more per person on the well-being of people with IDD compared to the general population, yet significant preventable health disparities persist.[1] To address these disparities, systems must be able to identify and track experiences and outcomes in this population. There remain significant limitations in the ability to identify people with IDD in both national surveys and administrative data. Federal efforts to address disparities in the population with IDD have identified data linkages as a priority strategy to better understand prevalence, healthcare access, outcomes, and associated costs.[2]

[1] 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.

[2] 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

Populations Studied

Maine residents with health care records in the MHDO APCD and MHDO Hospital Encounter Database. The MHDO APCD contains health care eligibility and medical, pharmacy, and dental claims records from commercial and public payors. MHDO's APCD includes 100% of the Medicaid and Medicare population and approximately 70% of the commercially insured population. 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; in any given year, the database includes almost 60% of Maine's population.

Study Design

The 2018-2022 MHDO APCD and Hospital Encounter Database were merged using MHDO's de-identified person-index key (or de-identified Person ID), which assigns a single set of demographic characteristics to a person, to produce an unduplicated dataset with all services and procedures and associated diagnoses for all persons with an available de-identified Person ID. People of all ages were included in the analysis.

There are a variety of methods available to identify populations for health surveillance research. We used an approach derived from the Clinical Classifications Software Refined (CCSR) tool, developed by the Health Care Utilization Project (HCUP) under the Agency for Health Care Research and Quality (AHRQ), and the Centers for Medicare & Medicaid Services' Chronic Conditions Data Warehouse (CCW). These were used in tandem to create a list of International Classification of Diseases-Tenth Revision (ICD-10-CM) diagnosis codes classified as IDD diagnoses. Scan QR code below to view Table 1 in the Appendix for a list of inclusion codes.

If a person had at least one medical claim or hospital inpatient or hospital outpatient encounter 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. Scan QR code to view Table 2 in the Appendix for a list of IDD subcategories and their corresponding inclusion codes.

Because a person's insurance may change over time, we also created a person-level flag to identify what payor or payors a person was covered by across the five-year period.

Limitations

We used diagnosis codes to identify people with IDD and if an IDD diagnosis was not coded on the claim and a person had IDD, we would not capture them in this analysis, resulting in an undercount of the population. In future analyses we may want to broaden our reach of 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. Furthermore, the MHDO APCD and Hospital Encounter Database represent those individuals who utilized healthcare services during the study period of interest, also likely resulting in an undercount of the IDD population.

Preliminary Findings

59,708 DISTINCT INDIVIDUALS WITH IDD

We identified 59,708 distinct individuals with IDD based on data in the 2018-2022 merged MHDO APCD and Hospital Encounter Database. This represents 3.7% of the total MHDO APCD and Hospital Encounter Database population during the study period (1,612,590 distinct individuals). For the non-mutually exclusive IDD subcategories:

46.1% — **27,531** (46.1%) had an autism, pervasive developmental disorder, or Asperger's syndrome diagnosis

42.9% — **25,603** (42.9%) had a learning disability with or without another developmental disability

23.4% — **13,987** (23.4%) had an intellectual disability diagnosis, with or without a developmental disability diagnosis

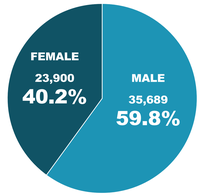
Of the 137 ICD-10-CM IDD Diagnosis Codes used in the analysis, the following are the top 10 IDD principal diagnoses among the IDD population, excluding individuals with only scholastic learning disabilities.

Rank	ICD-10-CM Diagnosis Code	Percentage of Individuals
1	F840 Autistic disorder	25.3
2	F802 Mixed receptive-expressive language disorder	11.6
3	F800 Phonological disorder	11.4
4	F70 Mild intellectual disabilities	11.3
5	F88 Other disorders of psychological development	9.0
6	F82 Specific developmental disorder of motor function	6.6
7	F79 Unspecified intellectual disabilities	6.1
8	F801 Expressive language disorder	6.1
9	F71 Moderate intellectual disabilities	6.1
10	F8089 Other developmental disorders of speech and language	3.4

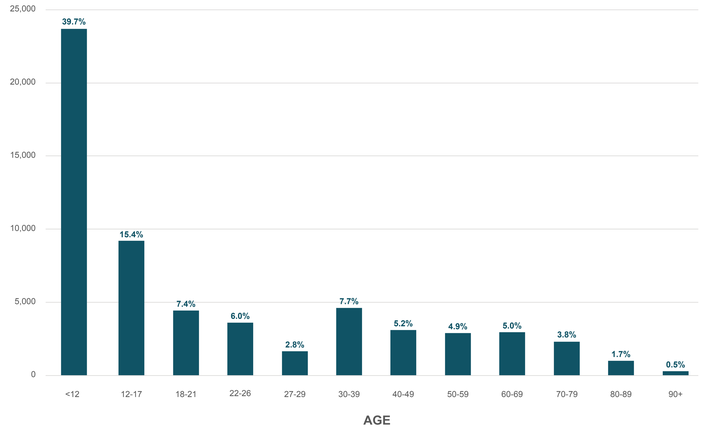
When looking at the demographic characteristics of individuals with an IDD diagnosis, males are overrepresented when compared to the study population (59.8% with IDD vs 48.2% overall). Children and young adults are also overrepresented.

Of the total number of individuals identified with IDD, 37,641 (63%) were Medicaid eligible across the study period. Of those with Medicaid, 7,429 (19.7%) were dual eligible for Medicare.

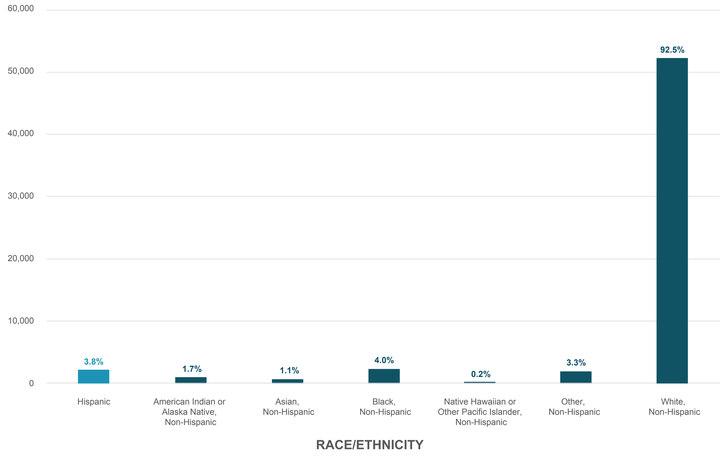
Individuals with IDD Diagnosis by Gender



Individuals with IDD Diagnosis by Age



Individuals with IDD Diagnosis by Race/Ethnicity



Conclusions

Identifying people with IDD accurately is fundamental to addressing health inequities within the population. Our assessment is that it is feasible to identify the IDD population using existing administrative data sources, such as APCDs and hospital encounter data, with the future potential of linking with other datasets, like disease registries and vital statistics records, for example. We demonstrate this in Maine to support future prioritization of this work within Maine and in other states.

There is potential for APCDs and hospital encounter data to provide states with information specific to the population with IDD, including:

- Co-occurring diagnoses (e.g., Cerebral palsy, behavioral health diagnoses, and chronic conditions)
- Utilization patterns such as emergency department use, prescription drug use, and ambulatory care sensitive conditions)
- Expenditures
- Stage of diagnosis for cancer compared to the general population

Preliminary analysis suggests that in the Maine Medicaid population, Blacks are over-represented as compared to the study population, but are under-represented as having an IDD diagnosis. This warrants further investigation by age and other demographic characteristics.

Acknowledgements

The Maine Health Data Organization (MHDO) is an independent state agency responsible for collecting health care data; creating and maintaining a useful, objective, reliable, and comprehensive health information database; and makes those data available to the broadest extent possible, while protecting individual privacy, to improve access, costs, and quality of health care services for Mainers.

Human Services Research Institute (HSRI) is a nonprofit, mission-driven institute that provides research, evaluation, program implementation, and data and statistical services to help create sustainable, person-driven systems. HSRI's Population Health Team builds data systems to collect, analyze, and report health care data to improve the quality of health information available for research, policy, and practice. HSRI's Intellectual and Developmental Disabilities Team assists agencies in moving consistently in the direction of higher-quality, more person-directive, self-directed services.

Appendix:

Table 1. List of ICD-10-CM codes used to identify a person with an IDD diagnosis

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
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
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
Q998	Other specified chromosome abnormalities

Table 2. List of ICD-10-CM codes used to identify IDD subgroups

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