

**Unlocking the potential of state level data:
Opportunities and promising practices for using state level data for
monitoring health and related outcomes in people with intellectual
and developmental disabilities**

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Abstract

No single U.S. health surveillance system adequately describes the health of people with intellectual and developmental disabilities (IDD). Researchers and policy makers have sought to understand the potential of state and local administrative and survey data to produce a local as well as national picture of the health of the population with IDD. Analyses of these secondary data sources have significant appeal because of the potential to derive new information without the burden and expense of new data collection. The authors examined the potential for data collected by states and territories to inform health surveillance in the population with IDD, including data from the administration of eligibility-based supports, health insurance claims and surveys administered for monitoring and quality improvement. While there are opportunities to align and harmonize datasets to enhance the available information, there is no simple path to use state and local data to assess and report on the health of the population with IDD.

Recommendations for policy, practice, and research include the development and use of consistent operational definitions in data collection, and research to fill knowledge gaps.

Introductory articles in this special issue detail the policy and public health imperative to collect and use accurate data to describe the health of people with intellectual and developmental disabilities (IDD). While investigations to-date have demonstrated significant gaps in the ability to identify and track their health using existing national health surveys (Krahn & Fox, 2013, Fujiura *et al*, 2010), policy makers and researchers have recognized that people with IDD may be identifiable in administrative datasets. These administrative data are derived from the administration of support services for people with IDD, health records, and surveys used for state monitoring and quality assurance by programs. This paper explores opportunities to use data collected at state and local levels in the administration and monitoring of disability support services to better understand the health of the population with IDD.

The challenge of unlocking the potential of state level data for health surveillance is at least three-fold. First, it is necessary to establish intra-state approaches that consistently identify this population and examine available measures of health and risk factors across available data platforms. Second, for an inter-state view across state systems or at the national level, state level data must be collected in ways that allow the data to be combined across multiple states. Finally, there must be processes to assure that data at the state and local level are reliably cleaned, linked and routinely examined to monitor the status of, and changes in, the health of people with IDD.

Background

The potential of state level data as a source for national health monitoring in the IDD population has been the subject of effort and inquiry in several related studies. In 2011, using a national consensus process, researchers established both conceptual and operational definitions

of intellectual disability (ID) for the purpose of health surveillance (Figure 1). They also developed a conceptual approach to identifying the population with ID in existing datasets (Figure 2) (Bonardi et al. 2011). The Population Identification Pathway (Figure 2) demonstrates an approach to identifying the population with ID and examples of data sources that allow to the inclusion of people who have ID but are not eligible for services.

<Insert Figure 1 and Figure 2 about here >

A compendium of Health Data Sources for Adults with Intellectual Disabilities (Center for Developmental Disabilities Evaluation and Research, 2011) detailed survey and administrative data sources and categorized into those that had low, medium, and high potential to inform health surveillance in the population with ID. The Compendium detailed potential data sources and identified challenges with using those sources. For those with the highest potential to inform health surveillance, limitations remained (e.g., the dataset including only a subset of people with ID, challenges in distinguishing from people with related cognitive impairment, or the need to complete data linkages in order to have health information for people identified with ID).

This initial study focused on the identification of the population with intellectual disability (ID), particularly adults with ID. The current paper describes findings from related efforts which explored opportunities and barriers to achieving a robust picture of the health and other outcomes of an expanded population, the population of children and adults with intellectual and developmental disabilities (IDD) using state and local data sources.

Feasibility of State Level Data – An Eight State Pilot Project

In 2011, the first and second authors were part of a research team from Research Triangle Institute (RTI) and the University of Massachusetts Medical School which examined the feasibility of developing a comprehensive state health surveillance system for people with IDD. The team reviewed data sources and systems from eight states which were selected based on diversity of geography, population size, and approach to service delivery for adults with IDD; Arizona, Texas, Tennessee, Kentucky, South Carolina, Pennsylvania, Massachusetts, and Hawaii. Information gathered from each state included a review of data sources and accompanying data dictionaries, and an exploration of the feasibility of data abstraction to create a cross-state dataset. Stakeholder interviews were conducted in each state to obtain information about datasets with the potential to describe the health status of a portion of the state's population with IDD. Key informants isolated datasets with potential to identify the state's IDD population and/or provide relevant health surveillance data. Data abstraction profiles created by the research team organized details of the identified datasets. Potential data sources reviewed and considered included data from sources including the state developmental disabilities agency, education/transition programs, state corrections, health department/vital records, other state agencies, and Medicaid claims. Additional data sources considered, where applicable, included the states' All Payer Claims Database, National Core Indicators (NCI), disease registries, and data available from public health surveillance systems. The pilot project described potential data sources and identified challenges associated with the use of those data sources.

State and Local Data National Workgroup

To inform federal planning and project work related to the population with IDD in the United States, the Administration on Community Living convened a panel of stakeholders and national experts in late 2017. The purpose and context for the expert panel is described in earlier

papers in this special issue. A subcommittee of this group continued to meet in 2018 to examine and describe administrative datasets that might be used for health surveillance including monitoring racial, ethnic, geographic and linguistic determinants of healthcare access and outcomes. The group developed a white paper entitled *Enriching our knowledge; State and local data to inform health surveillance of the population with intellectual and developmental disabilities* (ACL, 2019). The white paper described administrative data sets that might be used for this purpose and provided examples of how administrative data has been used to identify and describe the health of people with IDD. The results of the workgroup deliberations are described below, with additional context provided by the first and second authors' findings from the eight-state pilot.

Using State Level Administrative Data for Health Surveillance

Health Information available from State IDD Service Agencies. Each state in the U.S. has an entity which is responsible for administering services and supports for people with IDD within their borders. As each state establishes their eligibility criteria, database inclusion varies across states. Some states have narrow eligibility criteria while others are broader and include specific 'related conditions' (Cooper, Sowers, Kennedy-Lizotte, 2017). Administrative records for state IDD service agencies are a key starting place for relevant data as, by virtue of states' eligibility criteria for inclusion, they are data sources that reliably identify people with IDD with high specificity. This is demonstrated in the Population Identification Pathway (Figure 2), in which eligibility for IDD services is the first step to identifying the population with IDD. While information about service recipients' health and social risk factors or outcomes will vary across state IDD service agencies, the administrative records will contain basic demographic and service utilization information.

There are, however, notable limitations to these data sources. First, the records are maintained for administrative purposes connected to service delivery not health surveillance. Second, the amount of information, especially health-related information, may vary within state's DD service populations based on service need; individuals with greater service needs (e.g., several medical diagnoses), it can be assumed, will receive more services than an individual who has fewer health conditions. Third, some states delegate administrative responsibilities to managed care organizations or to local government agencies. Decentralized administration and data collection can result in varied levels of detail in data that is available from one jurisdiction to another. Fourth, data may not be electronically archived and may instead be stored in paper files in local offices or be maintained off-site with service providers. Finally, because of service eligibility criteria administrative data sets fail to include people with IDD who are not receiving formalized state-agency supports (e.g., people with IDD who are diagnostically or financially ineligible, or who have not applied for these disability-specific services).

Medical service claims (Medicaid, CHIP, All Payer Claims Data). Similar to IDD services, every U.S. state and territory has a jurisdiction-wide entity responsible for administering the Medicaid program and the Children's Health Insurance Program (CHIP) for beneficiaries within their borders. Because Medicaid and CHIP programs are not disability-specific, administrative and claims data hold promise for identifying the population beyond those who are receiving services and supports through publicly-funded educational or eligibility based IDD-specific programs.

In recording a health care encounter, clinicians may identify people as having an IDD or a related condition using diagnostic codes from the International Classification of Diseases-9th

edition or 10th edition (ICD-9 or ICD-10). Using health care encounter data may allow identification of people with IDD who do not receive long-term supports and services administered by state IDD agencies (e.g. Medicaid, Medicare, and CHIP recipients who use only Medicaid State Plan or Early and Periodic Screening, Diagnostic, and Treatment services).

A major limitation of health care encounter and billing claims records are that they depend on (a) the clinician identifying and coding IDD at the time of that encounter, and (b) codes used for billing refer to the presenting clinical event which precipitated the encounter. The mere presence of IDD may not necessarily be the relevant clinical condition for that health care delivery instance. Billing and encounter records are therefore understood to likely produce an undercount of the population with IDD.

Currently, the CDC is funding several studies that use a defined set of ICD-9 or -10 diagnostic codes in concert with state Medicaid claims data in an effort to identify the population with IDD (CDC, 2016). Work is underway to extend this project and demonstrate the feasibility of examining IDD health through cross-state analyses of Medicaid data. These efforts inform methods to directly address some of the limitations of this data source, and improve its utility for health surveillance (McDermott et al., 2018).

Looking ahead, the Medicaid data landscape is being advanced by initiatives like the Medicaid and CHIP Business Information Solutions (MACBIS) project and the Transformed Medicaid Statistical Information System (T-MSIS). The Centers for Medicare and Medicaid Services (CMS) at the United States Department of Health & Human Services (HHS) uses the T-MSIS to gather key eligibility, enrollment, program, utilization, and expenditure data for Medicaid and CHIP (CMS, n.d.). Nearly all states have begun to report data into the T-MSIS with the aim of enhancing the timeliness of reporting and administration. T-MSIS claims data

include children with IDD whose Medicaid or CHIP funded services are provided in educational settings.

Medicare data. A substantial portion of adults with IDD are dually eligible for both Medicaid and Medicare programs. Because Medicare is usually the first payer for numerous health services for those who are dually eligible, any health surveillance on these populations using claims data would be incomplete without the Medicare claims. Historically, access to this data by states has been complicated and expensive. However, in 2018, CMS announced that it is “taking steps to unlock these important data and reduce the administrative burdens associated with obtaining them from CMS (CMS, 2018, p. 6).” States may now execute “data request attestations” (DRAs) through a streamlined process, replacing the previous Data Use Agreement (DUA) process.

All Payer Claims Databases (APCD). Beyond Medicaid and CHIP databases, state All-Payer Claims Databases (All-Payer Claims Database Council, n.d.) hold potential for better understanding the health of people with IDD. As the name implies, these databases are established by states as a warehouse of health insurance claims from all payers in a state that typically include commercial insurers, Medicaid, state employee health plans and, sometimes, Medicare. The databases enable utilization and cost comparisons across populations as well as the identification of disparities by group. The datasets are limited to data from people who (a) have health care coverage (in most states) and (b) whose health service utilization generated a claim in that year. States define rules for data collection differently, including whether self-insured plans are included and the degree to which participation by private insurers is mandatory (Diaz-Perez, 2019). Work is currently underway to harmonize rules via the APCD Council’s Common Data Layout for State APCDs (APCD-CDL™). As these data come from medical,

pharmacy, and dental claims, they are subject to the same limitations described for Medicaid data in the section above. In addition, state databases vary in terms of the information included, quality control practices mandated for the reporting sources, and data access procedures. The structure and information contained within claims differ as states have varying policies related to how payment for services is rendered (Anthem, 2018). For example, managed care models have resulted in variability that is usually determined by state legislation as to whether managed care providers are required to report actual costs or can report average costs. These average costs are imputed and less informative for financial modeling (Byrd & Verdier, 2011). Phillips, Houtenville and Reichard (2019) examined APCD claims from New Hampshire which combined Medicaid and private insurance claims, replicating the model used by McDermott et al. (2018) with Medicaid data. The analysis demonstrated that combining Medicaid claims with private insurance claims can produce better state level estimates of prevalence of people with IDD under the age of 65, as well as differences in health service use among people with IDD who have health insurance through Medicaid compared to those with private insurance.

Data collected by the Social Security Administration. The Social Security Administration (SSA) is a federal agency, however, it is considered here under state data sources because the SSA administers two of the largest government programs related to disability in each state: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). In 2016, there were 840,824 beneficiaries who received SSDI on the basis of ID, 14,716 on the basis of DD, and 64,112 on the basis of autism spectrum disorder (ASD) (Lauer & Houtenville, 2018).

Each year, the SSA updates the Disability Analysis File (SSA DAF), an analytical data file containing historical, longitudinal, and one-time data on beneficiaries. Data includes: (a)

beneficiaries with disabilities who were between the ages 18 and retirement age and who participated in the SSI and/or SSDI programs at any time between 1996 and the year of the file, and (b) SSI child beneficiaries who participated in the SSI program at any point from January 2005 through the year of the file. The SSA DAF contains data elements from several SSA administrative records systems, including the Disability Determination Service Processing File (i.e., 831/832 File) that contains the primary diagnosis upon which eligibility was determined and coded using the ICD-9 classification system, including eligibility codes for intellectual and developmental disability. Livermore, Bardos and Katz (2017) demonstrated in an analysis the potential to use SSA National Beneficiary Survey data across multiple rounds to describe working age adult SSI and SSDI beneficiaries with ID for the purpose of comparing this group to other working age SSI and SSDI beneficiaries.

In addition, SSA disability related records have been linked to Medicaid data and federal survey data, including the National Health Interview Survey (NHIS), Current Population Survey (CPS), and Survey of Income and Program Participation (SIPP) (McNabb et al., 2009). The CPS is the source of official federal employment and poverty statistics.

State Level Surveys

In addition to the variety of information available through Medicaid billing records, two surveys administered at the state level hold potential to capture health data and support health surveillance efforts. They are National Core Indicators and The Consumer Assessment of Healthcare Providers and Systems Home and Community Based Services Survey discussed below.

National Core Indicators. The National Core Indicators (NCI), a collaboration between the Human Services Research Institute (HSRI) and the National Association of State Directors of Developmental Disabilities Services (NASDDDS), supports the activities of NASDDDS-member DD state agencies to gather performance and outcome measures that track performance over time, establish national benchmarks, and compare results across states (HSRI & NASDDDS, 2019). Forty-six states and the District of Columbia participate in NCI data collection. States establish survey periodicity based on the state quality monitoring plan which balances need for timely data with the survey effort and may not collect survey data every year. States implement the survey using standardized sampling of a representative sample of service recipients. NCI provides a standard data collection tool, analyses, and produces publicly available reports that summarize data received for each state.

NCI's representative sampling approach allows researchers to examine a number of variables. These include access to preventive health screenings by race, ethnicity, residential type and employment status for the population served by a state DD agency (Scott & Havercamp, 2014; Bershadsky, Hiersteiner, Fay, & Bradley, 2014). Each year, participating states and the District of Columbia contribute to the NCI with survey data collected from over 20,000 adults. While each year's data collection provides a good national snapshot, longitudinal comparisons cannot be drawn because not all states participate in data collection every year. As this is a survey administered to people who are receiving formal IDD support services (at minimum, case management plus one additional service), the sample is limited. In 2012, NCI expanded the survey content to collect additional health information, including diagnoses of chronic health conditions and access to preventive screenings in a searchable, public database <https://www.nationalcoreindicators.org/charts/>. The large sample size offers a glimpse of the

health conditions in the adult population of people in receipt of supports funded through their state's IDD system.

The Consumer Assessment of Healthcare Providers and Systems Home and Community Based Services (CAHPS HCBS) Survey was developed to collect Medicaid beneficiaries' experiences with long term supports and services (LTSS) across disability populations. While the CAHPS HCBS protocols provide guidelines for survey administration, the sample design, and the platform for data collection, reporting, and analysis are determined and managed at the state or provider level. As with the NCI surveys, states are considering ways to use this survey tool to examine value-based purchasing initiatives concerning supports for people with IDD. To accomplish this goal, the state samples must be sufficiently large to allow for comparisons between providers across the jurisdiction (CMS, 2017). At present, few states have adopted full value-based purchasing approaches with HCBS and LTSS, however these efforts are anticipated to expand in future years.

State-level Public Health Surveillance Systems

Although many state surveillance systems for the general population are assumed to include some of the people with IDD, these sources are rarely able to disaggregate people with IDD. Some state-specific surveillance systems, such as the Behavioral Risk Factor Surveillance System (BRFSS), ask questions about disabilities but cannot separate respondents with IDD from other types of disabilities.

The Behavioral Risk Factor Surveillance System (BRFSS). The CDC's BRFSS uses population-level surveillance approaches and collects data from all states, the District of Columbia, and participating territories. The BRFSS questionnaire consists of a core component,

optional modules, and state-added questions. While each participating jurisdiction may add questions to their BRFSS instrument, the CDC does not edit, evaluate, or track the results of these questions. Data is entered into the Disability and Health Data System (DHDS) to create an interactive website for easy use by states (CDC, 2018a). The major limitations of the BRFSS for the purposes of health surveillance in the population with IDD are that it does not include a question for respondents to self-identify with IDD (although it does ask more broadly about cognitive disability) and it requires that respondents are able to respond to a telephone survey.

Health Department vital records. Mortality data are a potential source of retrospective health data for people with IDD. Mortality data from the National Vital Statistics System (NVSS) (<https://www.cdc.gov/nchs/nvss/index.htm>) are a fundamental source of demographic, geographic, and cause-of-death information. The NVSS is the oldest and most successful example of inter-governmental data sharing in public health. The shared relationships, standards, and procedures form the mechanism by which the National Center for Health Statistics (NCHS) collects and disseminates the nation's official vital statistics. Through the Research Data Center (RDC) (<https://www.cdc.gov/rdc/index.htm>), mortality files could be linked to Medicare/Medicaid or other data identifying people with IDD to determine the cause of death, providing clues to late-life morbidity in this population. Although the potential for linkage exists, the use of mortality data in health surveillance more generally is not widespread due to inherent limitations in specificity of reporting and the expense associated with utilizing RDC services.

Pregnancy Risk Assessment Monitoring System. All but California, Idaho and Ohio participate in the Pregnancy Risk Assessment Monitoring System (PRAMS) (DRH/NCCDPHP, 2019) , which currently contains information on about 83% of all U.S. births

(<https://www.cdc.gov/prams/index.htm>). PRAMS collects population-based data within each state on maternal attitudes and experiences before, during, and shortly after pregnancy. Because the core questions in the PRAMS do not ask about ID or DD; it is not helpful on its own. The PRAMS data has been linked in multiple states to other data sources that may provide IDD identifiers. For example, in Massachusetts, the PRAMS database is linked to a unique longitudinal surveillance system of Pregnancy to Early Life Longitudinal (PELL) data which can be used to identify mothers and children with ID from Massachusetts resident deliveries. The linked data enable study of risk and protective factors as well as health outcomes longitudinally over the lifespan and examination of the impact of pregnancy-related experiences on subsequent maternal and child health (Mitra et al, 2015).

Education and Transition Programs

As with IDD, Medicaid, and CHIP services, every state and territory in the U.S. also has a jurisdiction-wide entity responsible for administering public education for children within their borders. The Individuals with Disabilities Education Act (IDEA) (20 U.S.C. 1400 et seq.) requires that each state submit data about children who receive educational services under IDEA to the IDEA database of the U.S. Department of Education, Office of Special Education Programs, specifically about (a) those infants and toddlers, birth through age two, who receive early intervention services under Part C of IDEA and (b) children with disabilities, aged 3 - 21, who receive special education and related services under Part B of IDEA.

The NCES uses this database to report the number of children who receive special education services by disability type, race and ethnicity, and primary language spoken. The U.S. Department of Education produces annual reports, detailing the relative numbers of children

receiving supports by disability category and by race and disability (U.S. Department of Education, 2017), and also reports on English language learners.

There are some important limitations to using data from state education administration datasets. Most notably, there is a high degree of variability in the classification of special education categories across and within states. Children with IDD who have fewer educational support needs may be more likely to be captured in other disability categories or to be underrepresented in educational data than children with more significant disabilities. Again, lack of uniform data limits the comparisons that may be made between or across states (NCES, 2018).

In interviews with states, the educational system was viewed as a source of population identification, particularly for those who may not go on to access adult services. No clear pathway has been identified, however, to follow individuals into adulthood for the purpose of health surveillance.

Several states indicated either transition programs, postsecondary follow-up, or even job placement for individuals with IDD may be sources to identify individuals with IDD who are not receiving other services from the state DD agency. These connections are seen as a potentially important avenue to link to IDD individuals who “fall off” the surveillance grid during this critical transition from school to adulthood. Interviews with state participants indicate there has been limited communication between the DD state agency and the educational agency for the purpose of health surveillance. In Massachusetts, for example, outcomes are monitored for the population that ages into adult services from special education, but educational and earnings data are the focus of monitoring, with limited information on health. Because school systems generally are not responsible for monitoring the outcome of students once they age out of services at age 22, any ongoing surveillance would likely require the sharing of identifiable

student information, which can be problematic. The Family Educational Rights and Privacy Act (FERPA) of 1974 (FERPA, 1974) is federal legislation that must be considered when pursuing the use of educational records for the purpose of surveillance. Loosely analogous to the Health Insurance Portability and Accountability Act (HIPAA, 1996), FERPA protects individuals from disclosure of personally identifiable information without consent.

Disease Registries

Disease registries, which collect information about people with specific conditions for research, are an additional potential source of data. For example, DS-Connect®: The Down Syndrome Registry, hosted by National Institutes of Health (NIH) and the Down Syndrome Consortium, allows people with Down Syndrome (DS) to store detailed information about themselves to inform clinicians about the health of people with DS and to contribute to research that benefits people with DS (NIH, 2019). A major limitation of most registries is that they are voluntary, which means that their sample is not statistically representative of the population under study and is not useful for estimating prevalence.

The New Jersey Autism Registry is an example of a mandatory state registry. While state law requires licensed health care providers to report any child diagnosed with autism to the registry, parents may opt for the data to be held anonymously (New Jersey Department of Health, 2018). It is worth noting that mandatory registries may indeed yield useful information, however stakeholders have raised significant privacy and autonomy concerns (e.g., Autistic Self Advocacy Network, 2009).

Examining Available Data from the U.S. Territories

Parallel data collection in the U.S. territories (American Samoa, Commonwealth of the Northern Marianas Islands [CNMI], Guam, Puerto Rico, and U.S. Virgin Islands) is not as robust as that of the states and the District of Columbia. For example, while all five U.S. territories are included in the 10-year U.S. census, none are included in the American Community Survey (ACS), although Puerto Rico conducts a Puerto Rican Community Survey, which is equivalent to the ACS.

The U.S. territories contribute to BRFSS (and the DHDS) in only some data collection years. For example, in 2016, only three territories (Puerto Rico, Guam, and U.S. Virgin Islands) collected BRFSS data. The KIDS COUNT Data Center, supported by the Annie E. Casey Foundation, compiles data from a variety of sources including state programs in all 50 states, the District of Columbia, Puerto Rico and U.S. Virgin Islands, but not in American Samoa, CNMI, or Guam. The KIDS COUNT Data Center includes datasets with data elements on children that could be used to identify children with a potential IDD (e.g., fourth graders who scored below proficient reading level by disability status and children under the age of six whose parents expressed predictive concerns about their child's development). The U.S. Virgin Islands maintain Head Start and special education enrollment data which could help recognize the IDD population (e.g., estimates of the number of children with a disability, children below proficiency in developmental skills, children who have received a developmental screening, and children receiving Early Intervention services); however, these datasets are not useful in estimating true prevalence and can offer only limited information about health status.

While all of the territories participate in data collection for the U.S. Department of Education, Office of Special Education's Part C (infant toddler), Part H (school age), and 619 programs (preschool) programs, a limitation in this dataset's utility is that due to the small

numbers in low incidence categorical areas (e.g., deaf-blind), some data are suppressed in order to maintain the confidentiality of the children and youth who would otherwise be identifiable.

Additional disability-relevant data sources to which all territories contribute are related to the Assistive Technology (AT) and Vocational Rehabilitation programs. Under the AT program, funded through the Administration for Community Living (ACL), states and territories report AT usage and access data including demonstrations, loan of equipment, equipment recycling, and other variables. Under the Vocational Rehabilitation program, funded through the Rehabilitation Services Administration, U.S. Department of Education, states and territories contribute data that can be mined regarding participation and successful case closures.

The Human Resources Services Administration announced in November 2018 that the Maternal Child Health Bureau will start collecting data through piloting questions in two of the territories in 2019 as part of the National Children's Health Survey. The remaining three territories will have questions added to the survey the following year.

For the territories, the data collected for other publicly-financed services and supports, such as Medicaid, is more limited. The Medicaid systems in the territories are fundamentally different from those of the states and the District of Columbia, and as a result there are structural differences in service provision and available data. For example, none of the territories' Medicaid programs support intermediate care facilities for individuals with ID (ICF/ID) or Home and Community Based (HCBS) Medicaid waiver programs; most people with IDD in the territories live in their family home rather than in an institutional or community-based residential setting. This eliminates the availability of two major sources of US administrative (Medicaid) data that are available in the states. Further, entities in the territories that do provide IDD

services do not collect or report data in a standardized method because their services are privately-funded (Institute for Community Inclusion, 2015).

Examining Outcomes by Race, Ethnicity, and Language

In general, there are systemic challenges to valid and reliable data collection on race and ethnicity. In state administrative datasets, race, ethnicity, and primary language spoken may be self-reported, but this reporting is often not mandatory. Missing data limits the ability of states to analyze and report on these variables. Additionally, administrative datasets may not even request information on primary language spoken, further limiting an important variable for examining disparities.

CMS has approached the issue of missing race and ethnicity variables in administrative data in several ways. In one study, CMS worked with RTI to develop an imputed (or inferred) race and ethnicity algorithm. This algorithm, based largely on surname, has been found to improve classification marginally for Hispanic and Asian/Pacific Islander beneficiaries, but has not improved classification for American Indian/Alaska Natives or multiracial beneficiaries (Eicheldinger, 2008).

To improve the quality of administratively-derived race and ethnicity information, the Office of Minority Health, within CMS is also collaborating with the RAND Corporation to pursue an indirect estimation of race and ethnicity. Indirect estimation methods supplement or replace self-reported racial and ethnic identifiers with estimates based on other characteristics that are strongly associated with race and ethnicity. The National Academy of Science, Engineering and Medicine (formerly the Institute of Medicine) recommended the use of indirect estimation to monitor health disparities in care and to target quality improvement efforts as a

bridging strategy in the absence of direct race and ethnicity information (IOM, 2009, Recommendation 5-1). Goode, Carter-Pokras, et al, (2014) noted that to create and study health disparity interventions that are culturally and linguistically competent for people with disabilities within diverse populations may require approaches to research that acknowledge and measure the myriad cultural differences among people with disabilities effectively, rather than simply using race and ethnicity as proxies for culture.

Opportunities and Challenges in Data Linkage for Health Surveillance

This review has summarized the identified state level data sources with the greatest potential to create the picture of health access, utilization, and outcomes. Each dataset described, however, is only capable of providing a sketch, at best. Data linkages, which use a common individual identifier to align and connect datasets, hold the greatest potential to complete the image at the state level and across multiple states to create a national picture of the health of people with IDD.

Intra-state data linkages. In South Carolina, a partnership between the University of South Carolina and the state's repository of numerous administrative datasets created a disability "Data Cube" (AUCD, 2009). The SC Data Cube contains administrative records about thousands of users of numerous state programs (including Medicaid and Medicare), linked by unique identifiers. The Data Cube can provide, in real time, data about the proportion of service users by age, gender, race, and disability type. In addition, as each individual's identification number remains the same over time, data can be analyzed cross-sectionally or longitudinally to monitor change over time. A characteristics file in the Data Cube allows users to identify specific subpopulations (e.g., people with sensory disabilities, or of a particular race or ethnicity), and use

a denominator to calculate rates and percentages of people with particular diagnoses. Additional reporting granularity can be achieved through the use of ICD-10 codes or inclusion in registries for specific categorical groups (people with ID, ASD, and head and spinal cord injuries are included in registries of the state's Department of Disabilities and Special Needs). In the Data Cube, disability is primarily identified using Medicare and Medicaid billing data. In addition, possible instances of IDD are identified by the following: history of special education in public schools; purchase of medical equipment, supplies, and durable medical equipment; and receipt of services from state agencies that provide treatment or rehabilitation for people with disabilities. In some cases, information available from these state agencies can confirm disability diagnoses. Through the Data Cube's integrated data system, service and claims patterns can be examined to better understand the health of the population with IDD.

Other states such as Massachusetts, Ohio, and California have established data linkages between service utilization data and health claims. These linkages are generally accomplished on an ad hoc basis and are not yet systematized to allow for routine reporting or monitoring. However, recent emphasis by CMS and the Office of the Inspector General supporting use of Medicaid data by state IDD service departments, for example, may yield additional promising ongoing data linkages for future surveillance efforts (HHS Office of the Inspector, ACL, Office of Civil Rights, 2018).

Examining Data Across Multiple States: The CDC's Cross-state Medicaid Project

The Disability and Health Branch within the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the CDC is supporting researchers to investigate, access, and use Medicaid data to identify patterns of health and health care utilization for people

with IDD across multiple states. NCBDDD has funded ten states (Arkansas, Iowa, Kansas, Massachusetts, Michigan, Montana, New Hampshire, New York, Oregon, and South Carolina) to initiate or expand activities in examining Medicaid data for people with ID (CDC, 2018b). To date, state awardees have accessed and utilized Medicaid claims data within their state to identify patterns of health and health care utilization for child and adult beneficiaries with IDD. Findings from this work are emerging in published peer-reviewed journal articles (McDermott, Royer, Cope, et al., 2018; McDermott, Royer, Mann, et al., 2018) with other scientific papers in various stages of development.

Summary and Recommendations

Several priorities must be addressed to enhance the ability of states to collect and use data both for surveillance at the state level and for aggregate interpretation across states. Proposed actions are organized into three broad categories: develop consistent operational definitions in data collection, promote research to fill knowledge gaps, and encourage wide dissemination of research findings to inform health surveillance and outcomes for people with IDD.

Develop and Use Consistent Operational Definitions in Data Collection

1. Methods need to be implemented to achieve greater consistency in how persons with IDD are identified within and across state administrative data sets. Policy makers should promote greater consistency in through use of operational definitions to facilitate data linkages and harmonization of existing datasets across states. Definitions established by statute, such as the DD Act, should inform such definitions. Additionally, researchers should develop methods for standardizing inclusion and exclusion criteria in defining the

IDD population. Recent examples in the literature provide initial guidance (e.g., McDermott et al, 2018; Phillips et al, 2019).

2. Federal, state, and local government administrative databases should include data elements which consistently identify recipients with IDD and enable monitoring of health equity across race, ethnicity and primary language spoken within and across populations.

Promote Research to Fill Knowledge Gaps

3. Train and support data analysts or “super users” and administrators to use linked administrative datasets to both identify service users and support health surveillance inclusive of children and adults with IDD.
4. Establish communities of practice through which data analysts and state administrators can enhance their skills, learn from one another, and collaborate to harmonize health surveillance data for people with IDD across states.
5. Federal agencies should develop a learning collaborative of state and federal agencies that collect data on people with IDD to develop and test system changes for implementation. As states develop internal expertise, there must be ongoing development of state and federal administrators.
6. In recognition of limitations of existing data, HHS and federal agencies should consider the development of a longitudinal study of people with IDD to provide a representative life course perspective on transitions over the life span and to understand the experiences of people at the intersection of race, ethnicity, and IDD to better understand the health care barriers and improve health equity.

7. HHS and federal agencies should consider strengthening data collection opportunities in the territories through an inter-departmental work group that would fill in gaps on data from federal departments that currently do not collect data from the territories.
8. Federal and state policies are needed that ensure data collection efforts include the categories of ID, DD, and co-occurring mental health/behavioral health diagnoses to enhance prevalence estimates and inform health surveillance.

Dissemination of Health Surveillance Research Findings

9. Research findings and recommendations about health surveillance and outcomes for people with IDD should be disseminated in ways that are accessible to people with IDD. This includes publications and web-based materials that are cognitively accessible and present key findings that can be used by people with intellectual and developmental disability and their supporters to advocate with policy makers and others.
10. Ensure that dissemination of information about health surveillance and outcomes for people with IDD reaches a broad and cross-disciplinary audience of policy makers, researchers and other stakeholder groups.

References

- Administration for Community Living. (2018). History of the DD Act: Evolution of the Law. Retrieved from: <https://www.acl.gov/node/105>
- Administration for Community Living (2019). Enriching our knowledge; State and local data to inform health surveillance of the population with intellectual and developmental disabilities. In Press.
- All-Payer Claims Database Council. (n.d.). Frequently Asked Questions. Retrieved from <https://www.apcdouncil.org/frequently-asked-questions>
- All-Payer Claims Database Council. (n.d.). Common Data Layout for State APCDs (APCD-CDL™) Retrieved from : <https://www.apcdouncil.org/common-data-layout>
- Anthem Public Policy Institute. (2018). Achieving States' Goals for All-Payer Claims Databases. Retrieved from: https://www.antheminc.com/cs/groups/wellpoint/documents/wlp_assets/d19n/mzq1/~edisp/pw_g345393.pdf
- Assistant Secretary for Planning and Evaluation. (2016, December). Status of State Efforts to Integrate Health and Human Services and Data: 2016. Retrieved from: <https://aspe.hhs.gov/system/files/pdf/255411/StateHHSSystems.pdf>
- Association of University Centers on Disabilities. (2009, June 28). The Disability Cube Project of the South Carolina Interagency Office for Disability and Health. Retrieved from AUUCD Association of University Centers of Disabilities: https://www.aucd.org//template/news.cfm?news_i4315&id=17
- Autistic Self Advocacy Network. (2009, January 13). Comments on Proposed New Jersey Autism Registry. Retrieved from: <https://autisticadvocacy.org/2009/01/comments-on-proposed-new-jersey-autism-registry/>
- Bershadsky, J., Hiersteiner, D., Fay, M.L., Bradley, V. (2014) Race/Ethnicity and the Use of Preventive Health Care Among Adults with Intellectual and Developmental Disabilities. *Medical Care* 52(10)Suppl 3. S25-S31
- Bonardi, A., Lauer, E., Mitra, M., Bershadsky, J., Taub, S., Noblett, C. (2011). Expanding surveillance of adults with intellectual disability in the US. Center for Developmental Disabilities Evaluation and Research (CDDER). E.K Shriver Center University of Massachusetts Medical School. Retrieved from: <https://shriver.umassmed.edu/programs/cdder/health-surveillance-adults-intellectual-disability>
- Bonardi, A, Lauer E, Staugaitis, S, Bershadsky, J, Taub, S. (2011) Developing an Operational Definition of Intellectual Disability for the Purpose of National Health Surveillance. http://www.umassmed.edu/cdder/health_surveillance.aspx

- Byrd, VLH and Verdier, J. Collecting, Using and Reporting Medicaid Encounter Data: A Primer for States (Washington, DC: Mathematica Policy research, 2011).
- Centers for Disease Control and Prevention (2009) U.S. Surveillance of Health of People with Intellectual Disabilities: A White Paper. Available at:
http://www.cdc.gov/ncbddd/disabilityandhealth/pdf/209537-a_idmeeting-short-version12-14-09.pdf
- Centers for Disease Control and Prevention. (2016). Improving the Health of People with Mobility Limitations and Intellectual Disabilities through State-based Public Health Programs (CDC-RFA-DD16-1603). p. 1-37. <https://www.grants.gov/search-grants.html?agencyCode=HHS>
- Centers for Disease Control and Prevention. (2018a). Disability and Health Data System (DHDS). Retrieved from:
<https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html>
- Centers for Disease Control and Prevention. (2018b). Disability and Health State Programs Retrieved from: <https://www.cdc.gov/ncbddd/disabilityandhealth/programs.html>
- Centers for Disease Control and Prevention. (2018c). Community Report on Autism 2018. Retrieved from: <https://www.cdc.gov/ncbddd/autism/addm-community-report/what-is-addm-network.html>
- Center for Developmental Disabilities Evaluation and Research (2011.) Compendium of Health Data Sources for Adults with Intellectual Disabilities. Retrieved from
[https://shriver.umassmed.edu/sites/shriver.umassmed.edu/files/documents/Compendium%20of%20Health%20Data%20Sources%20for%20Adults%20with%20Intellectual%20Disabilities%20\(PDF\).pdf](https://shriver.umassmed.edu/sites/shriver.umassmed.edu/files/documents/Compendium%20of%20Health%20Data%20Sources%20for%20Adults%20with%20Intellectual%20Disabilities%20(PDF).pdf)
- Centers for Medicare and Medicaid Services (2018, December 19). Ten opportunities to better serve individuals dually eligible for Medicaid and Medicare. SMDL #18-012. Retrieved from: <https://www.medicare.gov/federal-policy-guidance/downloads/smdl18012.pdf>
- Centers for Medicare and Medicaid Services. (n.d.). Transformed Medicaid Statistical Information System (T-MSIS). Retrieved from: <https://www.medicare.gov>
- Centers for Medicare & Medicaid Services (2017) HCBS CAHPS Technical Assistance Guide. Retrieved from <https://www.medicare.gov/medicaid/quality-of-care/downloads/hcbshaps-admin-ta-guide.pdf/medicaid/data-and-systems/macbis/tmsis/index.html>
- Centers for Medicare and Medicaid Services, Office on Minority Health. (2015, September). The CMS Equity Plan for Improving Quality in Medicare. Retrieved from:
https://www.cms.gov/about-cms/agency-information/omh/omh_dwnld-cms_equityplanformedicare_090615.pdf.

- Cooper, R., Sowers, M., & Kennedy-Lizzotte, R. (2017, September). Summary of Survey Results: State I/DD Operating Agencies. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services.
- Diaz-Perez, M., Hanover, R, Sies, E., Rupp, D., Courtemanche, J. & Levi, E. (2019). Producing Comparable Cost and Quality Results From All-Payer Claims Databases. *The American Journal of Managed Care*. 25. e138-e144.
- Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion (2019). Pregnancy Risk Assessment Monitoring System. <https://www.cdc.gov/prams/about/prams-faq.htm>
- Eicheldinger, C., & Bonito, A. (2008). More accurate racial and ethnic codes for Medicare administrative data. *Health Care Financing Review*, 29(3), 27-42.
- Eunice Kennedy Shriver National Institute of Child Health and Human Development. (n.d.). Data Sharing for Demographic Research: Data Harmonization. Retrieved from <https://www.icpsr.umich.edu/icpsrweb/content/DSDR/harmonization.html>.
- Family Educational Rights and Privacy Act of 1974, (FERPA) 20 U.S.C. § 1232g (1974).
- Fujiura G.T., Rutkowski-Kmitta V. & Owen R. (2010) Making measurable what is not so: National monitoring of the status of persons with intellectual disability. *American Journal of Intellectual and Developmental Disabilities* 35, 244-258.
- Goode, T., Carter-Pokras, O., Horner-Johnson, W., & Yee, S. (2014). Parallel tracks: Reflections on the need for collaborative health disparities research on race/ethnicity and disability. *Medical Care*, 52 (10) S3-S8
- Harrington, C., & Kang, T. (2016) Disparities in service use and expenditures for people with intellectual and developmental disabilities in California in 2005 and 2013. *Intellectual and Developmental Disabilities*, 54 (1), 1-18. doi:10.1352/1934-9556-54.1.1
- Havercamp, S.M., Krahn, G., Larson, S. & the National Health Surveillance for IDD Workgroup (2019). Working Through the IDD Data Conundrum: Identifying People with Intellectual and Developmental Disabilities in National Population Surveys. Washington, DC: Administration on Intellectual and Developmental Disabilities.
- Health and Human Services, Office of Minority Health. (n.d.). National Partnership for Action to End Health Disparities, Glossary of Terms. Retrieved from: <https://minorityhealth.hhs.gov/npa/templates/browse.aspx?lvl=1&lvlid=34>.
- Health Insurance Portability and Accountability Act of 1996 (HIPAA); Pub.L. 104–191, 110 Stat. 1936
- Human Services Research Institute and NASDDDS (2019). National Core Indicators. Retrieved from: <https://www.nationalcoreindicators.org>.

- Institute for Community Inclusion, RTC on Community Living, and The State of the States in Developmental Disabilities. (2015). Services for people with intellectual and/or developmental disabilities in the US territories. University of Massachusetts Boston, University of Minnesota, and University of Colorado. Available: <https://www.acl.gov/sites/default/files/programs/2017-03/Combined-Territories.pdf>
- Institute of Medicine. (2009). *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*. The National Academies Press, Washington, DC.
- Krahn G., Fox M. (2013) Health Disparities of Adults with Intellectual Disabilities: What do we know? What do we do? *Journal of Applied Research in Intellectual Disabilities* doi: 10.1111/jar.12067
- Lauer, E.A. & Houtenville, A.J. (2018). Annual Disability Statistics Compendium: 2017. Durham, NH: University of New Hampshire, Institute on Disability.
- Livermore, G., Bardos, M., Katz, K. (2017) Supplemental Security Income and Social Security Disability Insurance Beneficiaries with Intellectual Disability, Social Security Bulletin. Vol 77 No. 1
- Lulinski, A., & Tanis, E.S. (2018). The State of System Rebalancing in Illinois: FY 2017 Update. Data Brief (3). Aurora, CO: Department of Psychiatry, University of Colorado Anschutz Medical Campus.
- Magaña, S., Parish, S., Morales, M.A., Li, H., & Fujiura, G. (2016). Racial and ethnic health disparities among people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 54(3),161-172.doi: 10.1352/1934-9556-54.3.161.
- McDermott, S., Royer, J., Cope, T., Lindgren, S., Momany, E., Chul Lee, J., et al. (2018). Using Medicaid Data to Characterize People with Intellectual and Developmental Disabilities in Five U.S. States. *American Journal on Intellectual and Developmental Disabilities*: July 123(4),371-381. doi: 10.1352/1944-7558-123.4.371.
- McDermott, S., Royer, J., Mann, J.R. & Armour, B. (2018). Factors associated with ambulatory care sensitive emergency department visits for South Carolina Medicaid members with intellectual disability. *Journal of Intellectual Disability Research*, 62(3), 165-178.
- McDonald, K.E., & Raymaker, D.M. (2013). Paradigm shifts in disability and health: Toward more ethical public health research. *American Journal of Public Health*, 103(12), 2165-2173.
- McNabb, J, Timmons, D, Song, J, Puckett, C. (2009). Uses of Administrative Data at the Social Security Administration. Social Security Bulletin, Vol. 69, No. 1, 2009. Retrieved from: <https://www.ssa.gov/policy/docs/ssb/v69n1/v69n1p75.html>

- Mitra, M., Parish, S.L., Clements, K.M., Cui, X., Diop, H., (2015) Pregnancy Outcomes Among Women with Intellectual and Developmental Disabilities. *American Journal of Preventive Medicine*, 49(2), 300-308.
- National Center for Education Statistics (2018) The Condition of Education: Children and Youth with Disabilities. (n.d.). Retrieved from https://nces.ed.gov/programs/coe/indicator_cgg.asp
- National Center for Health Statistics. (2015). National Health Interview Survey on Health Statistics. Centers for Disease Control and Prevention. Available at: https://www.cdc.gov/nchs/nhis/nhis_disability.htm.
- National Institutes of Health. (2019). Down-Syndrome Connect. Retrieved from: <https://dsconnect.nih.gov>.
- New Jersey Department of Health. (2018, September 20). The New Jersey Autism Registry. Retrieved from <https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html>
- U.S. Department of Health and Human Services Office of the Inspector General, Administration for Community Living, Office of Civil Rights. (2018) Ensuring Beneficiary Health and Safety in Group Homes Through State Implementation of Comprehensive Compliance Oversight.
- Office of the Washington State Auditor. (2013). Performance Audit: Developmental Disabilities in Washington: Increasing Access and Equality. Retrieved from: http://www.sao.wa.gov/state/Documents/PA_DevDisabilities_Access_ar1009938.pdf#search=intellectual%20disability
- Phillips, K.G, Houtenville, A.M. & Reichard, A. (2019) Using all-payer claims data for health surveillance of people with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*. 63(4), 327-337.
- Scott, H.M. & Haverkamp, S.M. (2014). Race and health disparities in adults with intellectual and developmental disabilities living in the United States. *Intellectual and Developmental Disabilities*, 52(6), 409-418. doi:10.1352/1934-9556-52.6.409.
- The Lewin Group. (2010). Individuals Living in the Community with Chronic Conditions and Functional Limitations: A Closer Look. Office of the Assistant Secretary for Planning and Evaluations United States Department of Health and Human Services.
- U.S. Census Bureau. (n.d.) Institutionalized population. Retrieved from https://factfinder.census.gov/help/en/institutionalized_population.htm
- U.S. Department of Education (2017). 39th annual report to Congress on the implementation of the Individuals with Disabilities Education Act. Office of Special Education and Rehabilitative Services. Available: <https://www2.ed.gov/about/reports/annual/osep/2017/parts-b-c/39th-arc-for-idea.pdf>

U.S. Department of Health, Education, and Welfare. (1972, September). Mental retardation source book of the DHEW. Washington, DC: Author.

Figures

Figure 1. Operational Definition of Intellectual Disability Used in Feasibility Study

**** If a person can be included in the first four parts (#1, #2, #3, and #4 below), OR they are in the fifth (#5), then they will be considered to be part of the group ‘Adults with Intellectual Disability’ by researchers when collecting information about population health. ****

[#1] Person has been tested and has an IQ score of approximately 70 or below, OR a clinician has told the person that they have an intellectual disability, OR the person has a “related condition” along with support needs because of difficulties in learning, concentrating, or problem solving. Related conditions are specific diagnoses that often cause an intellectual disability, such as Down Syndrome or Prader-Willi Syndrome. [Intellectual Abilities and Related conditions] AND [#2] person needs support with activities of daily living (ADL) or instrumental activities of daily living (IADL). These are things like dressing, bathing, shopping, cooking, transportation, communication, or money management. Support can be ‘formal’ (for example, staff, help with housing, Social Security if a person can’t work), or ‘informal’ (family or friends helping) [Adaptive behavior] AND [#3] person was diagnosed with an intellectual disability or related condition in the ‘developmental period’. The time in a person’s life from childhood to becoming an adult is called the ‘Developmental Period.’ [Age of onset] AND [#4] person is expected to have the intellectual limitation their entire life. Depending on the person’s life circumstances, they may need formal or informal supports for their entire life in order to participate and live in their community. [Life-long] OR [#5] person is eligible for State or Federal public support programs because they have an intellectual disability. Examples of public support programs are Social Security Income (SSI), Social Security Disability Income (SSDI), other federal programs that specifically support people with a disability or services from a state disability agency. [Support needs]

Figure 2: Population Identification Pathway

Population Identification ‘Pathway’

	Population Identification Step	Data Example	Include?
<div style="display: flex; flex-direction: column; align-items: center;"> <div style="background-color: #0056b3; color: white; padding: 5px; margin-bottom: 10px;">Specificity</div> <div style="margin-bottom: 10px;">↑</div> <div style="margin-bottom: 10px;">↓</div> <div style="background-color: #0056b3; color: white; padding: 5px;">Sensitivity</div> </div>	1. Determined eligible for I/DD services?	<ul style="list-style-type: none"> State I/DD systems admin data. National Core Indicators (health questions) 	Yes
	2. IQ approximately 70 or below	<ul style="list-style-type: none"> Diagnosis code in administrative data Clinical diagnosis recorded in electronic data systems (e.g. Dept of Corrections) 	Yes
	3. Diagnosis of ‘related condition’	<ul style="list-style-type: none"> Administrative data BRFSS 	<u>Only</u> with support need, developmental, long term.
	4. Hx of receiving Special Education	<ul style="list-style-type: none"> Special education eligibility category data. (‘Intellectual disability/MR’) adequate for inclusion, other categories need additional screening 	