Enriching our Knowledge: State and Local Data to Inform Health Surveillance of the Population with Intellectual and Developmental Disabilities

Administration on Intellectual and Developmental Disabilities
Administration for Community Living

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Acknowledgements

As Deputy Commissioner of the Administration on Disabilities, I am pleased to present this report *Enriching our Knowledge: State and Local Data to Inform Health Surveillance of the Population with Intellectual and Developmental Disabilities.* This is the second of two companion reports that resulted from a highly productive partnership of public and private sectors to address the need for better data on the health of people with intellectual and developmental disabilities.

This report examines promising practices for using administrative data at the state and local level to develop an understanding of the health status and health needs of adults with intellectual and developmental disabilities. It describes efforts underway in several states identified through the National Association of State Directors of Developmental Disabilities Services and highlights ongoing work of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) to identify the health promotion needs of this population.

I'm deeply thankful for the collaborations with the other HHS agencies who committed their effort and attention to this initiative, most notably the NCBDDD and NCHS of the CDC. This work was accomplished through the efforts of state programs, researchers, and disability organizations—particularly AUCD, NASDDDS, and HSRI—that generously contributed their time, and with the leadership of Alixe Bonardi and Gloria Krahn. Finally, I gratefully acknowledge the contributions of Andrew Morris of CPE, ACL, who provided the internal management and coordination that brought this report to completion.

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Acronyms

AAIDD	American Association on Intellectual and Developmental Disabilities
ACL	Administration for Community Living, HHS
ACS	American Community Survey
AIDD	Administration on Intellectual and Developmental Disabilities, ACL, HHS
ASD	Autism Spectrum Disorder
ASPE	Assistant Secretary for Planning and Evaluation
AT	Assistive Technology
AUCD	Association of University Centers on Disabilities
BRFSS	Behavioral Risk Factor Surveillance System
CAHPS HCBS	Consumer Assessment of Healthcare Providers and Systems HCBS Survey
CDC	Centers for Disease Control and Prevention
CMS	Centers for Medicare & Medicaid Services
CERIIDD	Center for Epidemiological Research for Individuals with Intellectual and Developmental Disabilities
CHIP	Children's Health Insurance Program
CPS	Current Population Survey
DD	Developmental Disabilities
DD Act	Developmental Disabilities Assistance and Bill of Rights Act of 2000
DoDD	Department of Developmental Disabilities
FERPA	Family Educational Rights and Privacy Act
HHS	Health & Human Services, U.S. Department of
HCBS	Home & Community Based Services
IEP/IFSP	Individualized Education Program/Individualized Family Service Plan
HRSA	Health Resources and Services Administration, HHS
HSRI	Human Services Research Institute
ICD-9/10	International Classification of Diseases, Ninth and Tenth Revisions
ICF/ID	Intermediate Care Facilities for Individuals with Intellectual Disability
ID	Intellectual Disability
IDD	Intellectual and Developmental Disabilities
IDEA	Individuals with Disabilities Education Act
LTSS	Long-term Supports and Services
MACBIS	Medicaid and CHIP Business Information and Solutions
NACDD	National Association of Councils on Developmental Disabilities
NASDDDS	National Association of State Directors of Developmental Disabilities Services
NCBDDD	National Center on Birth Defects and Developmental Disabilities
NCES	National Center for Education Statistics, DOE
NCI	National Core Indicators
NHIS	National Health Interview Survey
OMH	Office of Minority Health, CMS
OMH	Office of Minority Health, HHS
SIPP	Survey of Income and Program Participation

SSA	Social Security Administration
SSA DAF	Social Security Administration Disability Analysis File
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
T-MSIS	Transformed Medicaid Statistical Information System

Executive Summary

Over the past 20 years, services and supports for people with intellectual and developmental disabilities (IDD) have changed significantly. The vast majority of adults with IDD now live in home and community-based settings rather than institutions. Data are collected on the IDD population's use of public programs (e.g., Medicaid and Social Security), their places of residence, and their employment status; however, the health status of people with IDD has received much less surveillance attention. While there are many unknowns regarding the health status of people with IDD who live in the community, even less is known about those who live in the community but who do not receive state-administered IDD or other public services. What we know is that many people with IDD are included in the 5% of the U.S. non-institutionalized population requiring help with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) that in 2006 accounted for 23% of all spending in the country and half of all health care spending that year (The Lewin Group, 2010). This is the most recent public data analysis we were able to identify.

The primary challenge to health surveillance in this population relates to how the population can be identified in available data collection systems. For people who are eligible for and receiving long term supports and services (LTSS), their IDD may be included as a qualifying diagnosis; however, there is typically limited health information available in LTSS records. Most state administrative datasets do not capture people with IDD who are not receiving public services or are not known to the LTSS system. While national public health surveillance systems could be used to identify and inform the health surveillance of the entire population with IDD (including those who are not receiving publicly funded services), these surveillance systems do not uniformly identify people with an IDD, and do not provide the deep level of information that state data may provide.

This is one of two companion workgroup reports to address health data regarding people with IDD. In 2017, the Administration on Intellectual and Developmental Disabilities (AIDD) convened a meeting to examine issues related to health surveillance in the population with IDD. The meeting included cross-agency U.S. Department of Health & Human Services (HHS) subject matter experts, national disability organization experts, and nationally recognized researchers. Two workgroups were established in 2018 to investigate the issues in national surveillance and opportunities available through state and local administrative data.

The technical reports from the two workgroups are:

1. *Working through the IDD Data Conundrum: Identifying People with Intellectual and Developmental Disabilities in National Population Surveys* (2019), which is intended to address national prevalence data through national surveillance.
2. This report, *Enriching our Knowledge: State and Local Data to Inform Health Surveillance of the Population with Intellectual and Developmental Disabilities* (2019), is intended to explore opportunities for richer contextual information available from administrative data at the state, territory, and multi-state level.

This report describes state level administrative datasets and systems, data collection efforts and surveys that hold promise for describing the population with IDD. Many data systems do not capture the whole population of people with IDD; rather, they identify only that portion who receive specific services. In other population level datasets, people with IDD cannot be identified within the data. This report reviews promising approaches that identify people with IDD in state level data, and that allow state level data to be examined within and across state data systems, including examples of data linkages.

To contextualize the discussion on the collection and use of data at the state level, workgroup members interviewed leaders of relevant agencies in the states of California, Ohio, and Washington. These states, in addition to South Carolina, were highlighted because they provide examples of focused efforts in data collection and analysis that allow for the identification of people with IDD in their datasets, and for expanding race/ethnicity information on people with IDD with more granularity than previous dichotomizing on “non-Hispanic Whites” or “minority.” A cross-state Medicaid data project supported by NCBDDD of CDC demonstrates the use of

Medicaid data to examine aspects of health utilization in the population identified with intellectual disability (ID). This report includes key findings from the discussions with state leaders.

In identifying opportunities to provide richer information about the population with IDD using state level data, the workgroup also identified both challenges and considerations for future directions. Future directions proposed by the workgroup include consistent operational definitions in data collection; promoting research to fill knowledge gaps; and encouraging wide dissemination of research findings to inform health surveillance and outcomes for people with IDD.

I. Introduction

The Administration on Intellectual and Developmental Disabilities (AIDD), within the Administration on Community Living (ACL) of the U.S. Department of Health and Human Services (HHS), recognized the need to update prevalence estimates and health status information on people with intellectual and developmental disabilities (IDD) in the U.S. states and territories. The current best estimates of national prevalence and information on health status of people with IDD are based on data gathered by the National Health Interview Survey-Disability Supplement (NHIS-DS, 1994-95)—data that are almost 25 years old (National Center for Health Statistics, 2015).

Much has changed for people with IDD since data were collected in the NHIS-DS, for example, many more people with IDD now receive supports to live with their families or independently in their communities. Practices in the U.S. reflect a changing focus from an institutional-based service system to an integrated community-based one, and from a focus on externally-determined services to more individualized and person-centered approaches that support people with IDD in reaching their highest potential (McDonald & Raymaker, 2013). These changes are codified through notable additions to the Developmental Disabilities Assistance and Bill of Rights Act in 1984 (42 U.S.C. 6000 et seq.), the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1994 (U.S.C. 6000 et seq. as amended and repealed by 42 U.S.C 15000 et seq.) and the Developmental Disabilities and Bill of Rights Act of 2000 (DD Act) (42 U.S.C. 15001 et seq.); the Community-Based Alternatives for Individuals with Disabilities (Executive Order No. 13217, 2001); and by Home and Community Based Services (HCBS) reimbursement provisions under Medicaid state plan and waiver authorities (ACL, 2018).

Given the changes in laws and regulations over the past 25 years (and corresponding changes to data collection), AIDD recognized and sought to explore the potential utility of existing administrative data sources at the state and territory level for information on the IDD population. These data are contextually rich and could enhance federal and state programs, policies, and planning, while supplementing health surveillance information on people with IDD.

Other federal agencies are also seeking better data on the population with IDD. Notably in 2015, the Centers for Medicare and Medicaid Services (CMS) Office of Minority Health (OMH) formally recognized that people with disabilities are at risk for health disparities (CMS, 2015). For this report, the HHS Office of Minority Health (OMH) definition of health equity is used, which is the "attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and healthcare disparities" (HHS, n.d.).

A. The demand for improved data collection and use

State, local, and federal entities require population demographic and outcome data for effective fiscal projections, policy development, and program planning. While the precise rates of people with IDD are unknown, we believe that they are included in the 5% of the U.S. non-institutionalized population receiving support for activities of daily living (ADLs) and instrumental activities of daily living (IADSs) that, in 2006, accounted for 23% of all spending in the country and half of all health care spending that year (The Lewin Group, 2010). Improved and updated data are needed to better:

- determine the health status and health disparities of people with IDD in states and territories,
- understand the factors that affect the health of people with IDD,
- interpret the experience of people with IDD in intersecting populations that also experience racial and ethnic health disparities such as populations of American Indian/Alaska Natives and people living in the U.S. territories,
- identify disparities that people with IDD and co-occurring psychiatric or physical disorders experience as compared with peers with IDD and without co-occurring conditions, and with people without IDD but who have physical and psychiatric conditions.
- understand how people with IDD access and utilize publicly-funded services, including effects of social determinants and geographical variability of those services.

State and local data can provide an understanding of health and services for people with IDD based on intersecting variables. The analysis of these data can suggest promising directions for state, local, and national services and supports.

B. Efforts to date

AIDD convened a multi-agency, multi-stakeholder meeting in November of 2017. The purpose of this meeting was to bring together diverse expertise to review the status of health surveillance for people with IDD, determine methods for estimating prevalence, and identify potential directions for improving health surveillance data from among the array of emerging possibilities. Participants included representatives from:

- HHS: ACL, National Center for Health Statistics (NCHS), National Center on Birth Defects and Developmental Disabilities (NCBDDD), CMS, Assistant Secretary for Planning and Evaluation (ASPE), and OMH.
- National disability organizations: Association of University Centers on Disabilities (AUCD), Human Services Research Institute (HSRI), National Association of State Directors of Developmental Disabilities Services (NASDDDS), National Association of Councils on Developmental Disabilities (NACDD), and the Center for Epidemiological Research for Individuals with Intellectual and Developmental Disabilities (CERIIDD).

- University-based researchers from nine universities and academic centers with subject matter expertise in health surveillance of people with IDD: Cincinnati Children's Hospital Medical Center, Georgetown University, Ohio State University, Oregon State University, University of Illinois at Chicago, University of Colorado, University of Kansas, University of Minnesota, and University of New Hampshire.

Discussions included preliminary review of available data at the state level including statistical approaches that may hold promise for understanding populations. Through discussion of the best-available research and surveillance approaches, AIDD leadership endorsed continued efforts in two targeted areas:

1. Pursue efforts to enhance prevalence data through national surveillance, and
2. Explore opportunities for richer contextual information from administrative data at the state, territory, and multi-state level.

C. Charge to the workgroups

This led to the establishment of two workgroups with an overall purpose:

> *To prioritize and address the need for better data to understand the prevalence, health status, and health determinants of people with intellectual and developmental disabilities.*

The specific charge for the AIDD State and Local Health Data Workgroup was to:

> *Describe approaches for better standardization and utilization of state administrative datasets that can provide richer data on health status and factors that influence health (e.g., health care access and utilization, place of residence, service use) of people with IDD:*
>
> - *Identify the potential data sources: (e.g., Social Security Administration (SSA), commercial claims, Medicaid, other administrative claims);*
> - *Describe processes for some degree of standardization across states and datasets; and*
> - *Identify datasets that could be used at the state and territory level, including datasets that describe the population of children (birth-18 years old) with developmental disabilities.*

The report of the companion workgroup, *Working through the IDD Data Conundrum: Identifying People with Intellectual and Developmental Disabilities in National Population Surveys* (Havercamp, Krahn, Larson, et al, 2019), focuses on national surveillance of health of people with IDD.

II. Background

Information on the health of people with IDD is incomplete in several ways. National surveys do not include institutionalized populations, such as people living in intermediate care facilities, adult correctional facilities, juvenile facilities, skilled-nursing facilities, psychiatric hospitals and in-patient hospice facilities (US Census Bureau, n.d.). In previous decades, many adults with IDD lived in larger institutional settings, skilled nursing facilities and, more recently, in group homes. Because of this, substantial numbers of people with IDD have not been included in national health surveillance efforts. In the U.S., the censuses of publicly-operated institutions peaked in 1967 at 194,650 people (US DHEW, 1972). By fiscal year 2017 that number had fallen more than ten-fold to 18,431 people (Lulinski & Tanis, 2018). While many more people with IDD now live in the community, they are still at risk of being invisible in many health surveillance systems, as respondents with IDD may not be identifiable within the dataset and sampling frames may not take into account the unique residential characteristics of people with IDD. Magaña and colleagues (2016) suggest that national health surveys only identify about 60% of community-dwelling adults with IDD.

It is critical to understand the requirements of the population with IDD whose health needs are often more complex than the general population (Krahn & Fox, 2013), and whose living arrangements (e.g., group homes, shared living or foster homes) can present unique challenges to understanding health care access and health outcomes (Kozma, Mansell & Beadle-Brown, 2009). In the absence of a complete picture, efforts are underway to obtain more information from pre-existing sources and to identify other sources as they become available. In 2016, the Assistant Secretary for Planning and Evaluation conducted a survey regarding connections between state programs on health and human services, especially relating to data and data interoperability (ASPE, 2016).

Administrative datasets that are primarily collected for other purposes, such as concerning the receipt of or eligibility for services, have limitations for population surveillance use as they typically only include people known to or enrolled in service systems or programs (e.g., state DD services, Medicaid, Social Security). Some strategies for mining administrative datasets to identify people with IDD include analyses of state Medicaid data, data-linking across administrative datasets and data harmonization to combine information from different sources to provide a comparable view of data from different studies (Eunice Kennedy Shriver National Institute of Child Health and Human Development, n.d.). Additionally, in discussion with workgroup members, capture-recapture sampling was proposed as a method to explore for identifying and estimating the size of the population with IDD through the use of multiple datasets.

Other potential data sources include in-depth clinical studies examining issues unique to people with IDD, longitudinal studies to determine health trajectories across the lifespan, incident (e.g., serious injury or death) reporting datasets, and other large-scale data sources like the Healthy Athletes database of the Special Olympics and the National Core Indicators (NCI) of HSRI and NASDDDs. Using combinations of these data sources can provide a clearer and fuller understanding of the health of people with IDD at the state and territory level.

III. State Level Data Sources

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 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. Third, processes are necessary to assure that data at the state and local level is reliably cleaned, linked and routinely examined to monitor the status of, and changes in, the health of this population. The following sections describe promising state level sources of data and describe the opportunities and challenges in making the data useful for understanding the health of the population with IDD.

A. Using state level data to examine health outcomes

At neither the state nor federal level, no single dataset contains information about all people in the population with IDD; however, various sources of state and territorial level datasets hold promise to inform questions about the health status of people with IDD (Bonardi, et al, 2011). Of particular use might be state administrative records concerning services or supports provided through state IDD service agencies, educational programs, and other programs such as Temporary Assistance for Needy Families (TANF), Vocational Rehabilitation, Medicaid, or Medicare. Additional sources of survey data that may be useful are the National Core Indicators (NCI) survey, the Consumer Assessment of Healthcare Providers and Systems Home and Community Based Services survey (CAHPS HCBS), and the Behavioral Risk Factor Surveillance System (BRFSS). BRFSS is the data source used to populate the NCBDDD’s Disability and Health Data System (DHDS) (Centers for Disease Control and Prevention, 2018a).

The workgroup identified the state and territorial level data systems of IDD service agencies, school systems, and payers for health and LTSS as the most likely to collect relevant data in the course of documenting the receipt of, or eligibility for, services. The following section summarizes these data sources. Section IV highlights promising efforts by several states to more fully utilize their existing data sources.

i. State IDD Service Agencies

Every state in the U.S. has a jurisdiction-wide entity responsible for administering services and supports for people with IDD within their borders. As each state establishes their own criteria for service eligibility, people included within the resultant datasets vary across states. Some states have narrow eligibility criteria while others are broader and include conditions related to IDD (Cooper, Sowers, Kennedy-Lizotte, 2017).

Administrative records for state IDD service agencies are a good starting place for relevant data as, by virtue of states' eligibility criteria for inclusion, they are data sources that reliably identify people 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 for all individuals being actively supported.

There are however notable limitations to these data sources. First, these records were developed for the administration of service delivery purposes rather than for surveillance. Next, depending on the state, information may not be electronically archived; it may be stored in paper files in local offices or remain with service providers. Finally, as eligibility requirements and the collection of demographic data varies by state, a lack of uniform population and data definitions limit the comparisons that may be made across states. A further caveat to these data is that not all people with IDD who are deemed eligible, actually receive services, resulting in state waiting lists as well as unidentified people with IDD.

ii. Education and Transition Programs

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 2, who receive early intervention services under Part C of IDEA and (b) children with disabilities, aged 3 through 21, who receive special education and related services under Part B of IDEA.

Data from the IDEA database is also a good place to start to look for relevant data. 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.

Workgroup members also noted some 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.

iii. Medicaid and CHIP Claims Data

Every state and territory in the U.S. 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 are not specific to a disability type, administrative and claims data from these programs 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 with the International Classification of Diseases-9th edition or -10th edition (ICD-9 or ICD-10). In this way, people with IDD who are not already 'known' to the system of state-funded supports may be identified in large Medicaid datasets. A major limitation of health care encounter and billing claims records are that they depend on (a) the clinician identifying and coding IDD in the encounter record at the time of that encounter, and (b) codes used for billing refer to a presenting clinical event. The presence of IDD may not a relevant clinical condition for health care delivery. Billing and encounter records are therefore understood to likely produce an undercount of the population with IDD contained within those records. The CDC is currently funding several studies that use a defined set of ICD-9 or -10 diagnostic codes with state Medicaid claims data to identify the population with ID (CDC, 2016). Efforts are underway to extend this project and demonstrate the feasibility of examining health outcomes in the ID population through cross-state analyses of Medicaid data.

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). CMS 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.

Claims data available through T-MSIS can also be used to examine Medicaid-funded services that are included in an Individualized Education Plan (IEP) or Individualized Family Service Plan (IFSP) for a Medicaid eligible and enrolled child. Medicaid and CHIP funds may be used to pay for some health-related services provided under an IEP/IFSP for an enrolled child. The T-MSIS codes benefits types for Medicaid- and CHIP-funded school-based services associated with an IEP/IFSP.

iv. Data Collected by the Social Security Administration

The SSA is another potential source of information on people with IDD at the individual and state level. While a federal agency, it is included here 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, 840,824 beneficiaries 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. Its 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.

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

v. Additional State Level Databases

Additional state level databases also hold potential for better understanding of health of people with IDD, most notably state All-Payer Claims Databases (All-Payer Claims Database Council, n.d.). As the name implies, these databases offer a searchable warehouse of health insurance claims from all payers in a state, usually including commercial insurers, Medicaid, state employee health plans and, sometimes, Medicare. The database enables utilization and cost comparisons across populations and the identification of disparities by group. The datasets are limited to people who (a) have health care coverage and (b) whose health service utilization generated a claim in that year. While states define rules for data collection differently, work is currently underway to harmonize those rules.

B. State level surveys

i. National Core Indicators

NCI, a collaboration between HSRI and 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 (Human Services Research Institute & NASDDDS, 2019). Forty-six states and the District of Columbia participate in NCI but all states do not collect data each 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.

Participating states administer the survey to a representative sample of service recipients in their state. The data allow researchers to examine a number of questions, such as 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). Each year, participating states and the District of Columbia contribute to the NCI with survey data collected annually from over 20,000 adults. While each year's data collection provides a good national snapshot, longitudinal comparisons cannot be drawn as not all states participate in data collection every year. The sample includes only adults with IDD who are receiving supports (at minimum, case management plus one additional service). In 2012, NCI expanded the survey content to collect additional health information, including diagnoses of chronic health conditions and access to preventive screenings.

ii. Consumer Assessment of Healthcare Providers and Systems HCBS Survey

The CAHPS HCBS survey collects Medicaid beneficiary's experiences with LTSS. CMS developed this single survey for use 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. At present, few states have adopted full value-based purchasing approaches with HCBS and LTSS, but these efforts are anticipated to expand in future years.

C. State-level Public health surveillance systems

i. Behavioral Risk Factor Surveillance System

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 state-added questions to their BRFSS instrument, the CDC does not edit, evaluate, or track the results of these questions. Data are 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 this report are that it does not include a question for respondents to self-identify with IDD (although it does ask about cognitive disability) and it requires that respondents are able to respond to a telephone survey.

ii. 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 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 (National Institutes of Health, 2019). A major limitation of most registries is that they are voluntary, which means that the data collected are not statistically representative of the population under study and are not useful for estimating prevalence.

The New Jersey Autism Registry is an example of a state registry that is mandatory. 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).

D. Data collection in 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 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 collection, supported by the Annie E. Casey Foundation, is conducted 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 includes 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 ACL, HHS, 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.

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 HCBS waiver programs; most people with IDD in the territories live in their family home rather than in an institutional or community-based residential setting (Institute for Community Inclusion, 2015). This eliminates the availability of two major sources of 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).

IV. Examples of Uses of State IDD System Data

The workgroup focused discussion on four states that demonstrated promising practices to collect and use administrative data that describes the population with IDD. It should be noted that the workgroup did not conduct a comprehensive scan of all states, and the examples presented here are not intended to detail all activities using state and local data.

A. Increased outreach for identification

i. Washington: Efforts to Expand Identification Beyond the Service-Eligible Population With IDD.

Recognizing that a portion of the population with IDD may not be included among eligible service participants, the state of Washington has a legislatively-directed initiative that encourages reaching out to eligible persons who would otherwise be unidentified or unserved. State officials use an estimated prevalence of 1.2% for DD in Washington, or approximately 81,000–84,000 people (Office of Washington State Auditor, 2013). At present, there are about 45,000 people deemed eligible for services, of which approximately 32,000 are receiving some services and about 12,500 are on a ‘no-paid services’ caseload (people who are eligible but are not currently receiving services). State officials closely track people who are receiving services and produce reports on spending by services as well as by residential settings, race, and ethnicity, with comparisons to the general population. These data, as well as the NCI data, are made publicly available in the *Legislative Notebook* (The Arc of Washington State, 2018). Although it is recognized that a portion of the population is not currently identified that could benefit from support, representatives from Washington state were not aware of data that the state could use to track individuals who were not identified or who had been found ineligible for services.

At the time the workgroup interviewed representatives of Washington, the state was in the process of implementing changes to its HCBS waivers, most notably the delivery of certain behavioral health services through a managed care model. The move to a managed care system introduces additional challenges in the ongoing availability of data for population level monitoring. Specifically, unless otherwise directed, managed care organizations may restrict access to at least some beneficiary data, further limiting what is available for public analysis.

B. Linkages and harmonization to leverage multiple datasets

Several states are pioneering efforts to expand information derived from their datasets by combining data across administrative datasets. Data linking, or connecting information from different sources about the same person, is one approach that holds promise. For smaller groups within a population, such as people with IDD, dataset linkages can increase the types of analyses possible across a range of constructs. In contrast, data harmonization requires combining data from multiple datasets (with typically varying file formats, naming conventions, and columns) into one cohesive data set. Harmonized data can allow users to address targeted questions about prevalence and outcomes in the population. Because administrative datasets have been developed for multiple purposes, the harmonization of definitions, variables, constructs, and samples (any of which may have also changed over the data collection years), is a significant undertaking. Despite these requirements, data linkage and harmonization of existing state datasets may be a feasible way to address questions that cannot be answered within any one current dataset.

i. South Carolina: Expanding Knowledge through 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 to 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, researchers and administrators can examine service and claims patterns to better understand the health of the population with IDD.

ii. Ohio: Connecting Medicaid Data with State IDD Services Data

The Ohio Department of Developmental Disabilities (DoDD) uses data linkages to connect Medicaid records to active recipients of state DD services. This allows the DoDD to conduct robust analyses of targeted health services utilization by those it serves. During interviews with representatives of the state, it was emphasized that hiring a seasoned 'super-user' (a person with advanced expertise in accessing, manipulating, and interpreting the Medicaid data system) from the state's Medicaid agency into the DoDD was crucial to its ability to effectively analyze and generate reports using the Medicaid data. At present, Ohio is among a minority of state DD agencies that have the infrastructure and capacity to link and examine health claims data for the population served by the DD agency, making them uniquely positioned to explore opportunities for expanded and enhanced analyses.

C. Addressing equitable access to health and health care

i. California: Examining Utilization by Race, Ethnicity, and Language Spoken

California is the only state with an entitlement to IDD services. IDD services are provided to eligible individuals through 21 regional centers (California Department of Developmental Disabilities Services, 2018a, 2018b). To be eligible for IDD services in California, a person's condition must manifest before the person's 18th birthday, be expected to continue indefinitely, and present a substantial disability (California Department of Developmental Disabilities Services, 2018c). Conditions specified for eligibility include ID, CP, epilepsy, and ASD, as well as disabling conditions closely related to ID, or that require treatment similar to that for ID. Conditions that are solely physical in nature are not eligible for IDD services.

California has demonstrated promising methods that use administrative data in monitoring equitable access to services through internal linkages and comparisons with general population demographics. The California Department of Developmental Services (DDS) maintains several datasets which can be linked with the unique identifiers of service recipients. First, a client master file (CMF) includes all people served by the regional centers with demographic information. Second, the Client Development Evaluation Report (CDER) file contains information on diagnostic and clinical assessments, detailed annual data (i.e., physical abilities, language, vision, cognitive functioning, psychological status, social functioning, behavioral problems, medical conditions, special conditions, special aids, and care needs). Finally, the IDD Purchase of Service (PS) file includes service utilization and cost data. Data linkages can allow examination of service recipient characteristics such as race and ethnicity, services, and outcomes (e.g., Harrington & Kang, 2016).

Several other data collection, monitoring, and analyses are also under way in California. The state recently launched an initiative to monitor service utilization by, among other characteristics, race, ethnicity, language spoken, and residential status. In addition, the California Health Interview Survey provides baseline health data by each region of California, and its data can be compared with the general U.S. population.

D. Multi-state highlight: The CDC's cross-state Medicaid project.

CDC's NCBDDD - Disability and Health Branch is supporting the investigation of accessing and utilizing Medicaid data to identify patterns of health and health care utilization for people with intellectual and developmental disabilities across multiple states. As a major part of its mission, the NCBDDD works to improve the health and quality of life among people with mobility limitations and/or ID through adaptation and implementation of evidence-based strategies in states, U.S. territories, and tribal governments. NCBDDD recently 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). State awardees to date 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. As this report is being drafted, 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. Findings from these targeted state Medicaid data analyses are anticipated to lead to an evidence-based intervention, benefiting people with IDD, that will be implemented across states in subsequent years (personal communication, Catherine Okoro, May 17, 2018).

E. Targeted topics

i. Consideration of Datasets that Describe Adults and Children

The workgroup considered available datasets and methodologies for estimating prevalence and describing health indicators and other outcomes for children and adults with IDD. As noted above, Medicaid claims data provide one potential avenue for identifying both children and adults with IDD.

Prevalence estimates for children with ASD can be estimated from the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network, a group of programs funded by CDC to estimate the number of children with ASD and other DDs living in different areas of the country. The most recent estimates from the ADDM Network are based on data collected from the health and special education records of children living in 11 communities across the U.S. during 2014. For the ADDM study, cases were identified from multiple data sources through a systematic review of health and special education records, using behaviors described in comprehensive evaluation to identify children with ASD, some of whom may not have been previously diagnosed with ASD (CDC, 2018c). The ADDM methodology is a costly approach that relies on the quality and quantity of information in records, and, because data collection and review are resource-intensive, may not always be timely.

ii. Examining Outcomes by Race, Ethnicity, and Language

California provides an example of monitoring access to services and select outcomes by race, ethnicity, and language spoken. However, 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. They have worked with RTI International to develop an imputed (or inferenced) 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. To improve the quality of administratively-derived race and ethnicity information, OMH, 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 Institute of Medicine (now National Academy of Science, Engineering and 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 and colleagues 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 (Goode, Carter-Pokras, et al, 2014).

V. Barriers and Opportunities at the State Level

A. Barriers

Barriers to using existing state level data sources to estimate prevalence and inform health surveillance for people with IDD are those of definition, purpose, structure, privacy, and privatization. At the state level, criteria for service eligibility for people with IDD is not consistent. Additionally, administrative data are collected for specific purposes and held by the state through systems that, with few exceptions, are not designed for consistency or linkages.

While states may have rich health and educational data sets, laws prohibiting the sharing of personally identifiable information present challenges for fully mining or sharing these datasets for national analyses.

The datasets with the greatest potential information about the IDD population are those that focus on eligibility, identifying service need, and monitoring services and supports. Health surveillance, however, is not generally a priority or a function that can be accomplished within these datasets.

Finally, as health care delivery and payment capitations are moving towards managed care systems, increasingly, so are LTSS. Analysts and advocates have expressed the concern that the data held by managed care entities will not be routinely or universally available for population level analysis.

B. Opportunities

Emerging opportunities that utilize existing state level data sources to estimate prevalence and inform health surveillance for people with IDD rely on unifying definitions, expanding surveys, and employing more sophisticated methods for data linkages and study designs. Data linkages, such as South Carolina's Disability Cube, have demonstrated the possibility of aligning datasets to leverage segmented information to generate a fuller picture of the health and service utilization of both those who are receiving state IDD services and those who may have IDD but who are not known to the IDD system.

The continued expansion of electronic data systems, such as CMS's T-MSIS, holds promise that databases will enable the population with IDD to be identified uniformly across state lines.

Further, as described in the companion report on national surveillance, efforts are underway to improve survey methods and question refinement to enhance the ability to identify people with IDD in national population health surveys.

Finally, there are a number of national networks with tremendous expertise in IDD and research that could be leveraged for more sophisticated studies and analyses of state level data to estimate prevalence and inform surveillance of health outcomes and health determinants. Of particular value in these efforts are the following existing resources:

- The national network of DD Act programs, funded by AIDD, ACL, and present in all U.S. states and territories, who routinely collect and analyze information concerning people with IDD: the University Centers for Excellence in Developmental Disabilities (UCEDDs); the State Councils on Developmental Disabilities (DD Councils); and the State Protection & Advocacy Systems (P&As).
- The state IDD services, education, and Medicaid entities, who collect and maintain administrative and health claims records on people with IDD.
- Other state services and programs that collect and maintain administrative records, including TANF, Vocational Rehabilitation, Adult Protective Services, and Ombudsmen programs, which may be used by people with IDD.
- The network of 19 State Disability and Health Programs funded by NCBDDD, CDC.
- AUCD, through its National Center on Disability in Public Health, is seeking to build capacity by encouraging collaboration between public health partners and its member network. AUCD represents the national association of UCEDDs, Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs, and Eunice Kennedy Shriver Intellectual & Developmental Disabilities Research Centers (EKS-IDDRCs).

- The data Projects of National Significance, funded by AIDD, ACL.
- The NCI project of HSRI and NASDDDs, whose foci directly relate to understanding the population of IDD.

VI. Proposed Considerations for Future Directions

In developing this report, a number of overlapping and interlocking themes for future directions emerged, and various opportunities can be enhanced and leveraged health surveillance and examine health disparities for people with IDD. The workgroup identified several actions that federal and state agencies, not-for-profit organizations, and other IDD-stakeholder groups can consider when seeking to improve data collection related to people with IDD. These actions are organized in 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.

A. Develop consistent operational definitions in data collection

- Promote greater inclusion of race, ethnicity, and primary language spoken at home in data collection for people with IDD to enhance monitoring of health equity.
- Promote greater consistency in operational definitions to facilitate data linkage and harmonization.

B. Promote research to fill knowledge gaps

- Conduct a more complete scan of best practices in using administrative data on people with IDD across all states and territories.
- Promote the training of super-users of datasets that include records of people with IDD to improve access to, and linkages of, crucial data.
- Initiate a community of practice for administrators of state level datasets interested in identifying new measures and indicators in their existing datasets.
- Develop a learning collaborative of state and federal agencies that collect data on people with IDD to develop and test system changes for implementation. An example is the Disability Network Business Acumen Learning Collaborative (NASUAD, n.d.)
- Expand opportunities for data linkages to maximize the utility of current data collections.

- Investigate federal inter-agency partnerships to develop a longitudinal study of people with IDD to provide a representative life course perspective on transitions over the life span, which could inform policy and practice.
- Replicate demonstration projects that collect data on people with IDD (such as in Ohio, South Carolina, and California) to access and analyze Medicaid and CHIP claims data to better understand the health care needs and health outcomes of people with IDD.
- Establish quantitative and qualitative studies 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.
- 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.

C. *Encourage widespread dissemination of research findings to inform health surveillance and outcomes for people with IDD*

- Enhance the capacity of state entities to analyze and utilize available data sources in their jurisdictions.
- Expand the use of strategies identified by the state Medicaid data project, the initiative funded by NCBDDD, CDC, to harmonize data across states and territories.
- Identify and disseminate successful strategies states have used to enhance their data collection, data linkages and harmonization, and utilization of findings to inform policies and practices.
- Promote the use of public-private partnerships to develop new proofs-of-concepts, replicate effective strategies, and encourage the adoption of evidence-based practices in informing health surveillance and outcomes for people with IDD.
- Disseminate findings in ways that are accessible to the population with IDD to inform future health surveillance and outcomes for people with IDD.

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