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Title:

A Call for Better Data on Prevalence and Health Surveillance of
People with Intellectual and Developmental Disabilities

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Call for Health Data on People with IDD

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The U.S. approach to the health of people with intellectual and developmental disabilities (IDD) is fraught with paradox. The health of this population has been of longstanding concern, yet we understand their health less well than many other groups. The U.S. spends much more per person on the well-being of people with IDD compared to the general population, yet the outcomes of those expenditures are disappointing and include significant preventable health disparities. Even as expectations for people with IDD have changed to include better health and greater participation in their communities, eligibility for services that support these outcomes is rooted in expectations of dependence and poverty. This paper is a call for better data that considers a series of questions to provide context for understanding the need and directions for better health surveillance of people with IDD.

Why is Health Surveillance Important for People with Intellectual and Developmental Disabilities?

Federal and State Agencies Need for Better Data

In an era of data-informed decision-making and accountability, federal and state agencies are acutely aware of the need for better data on people with IDD. This is a population with highly complex needs across multiple areas. Federal and state agencies are responsible for providing services that include education, employment training, long term services and supports, and health care. Data on education, residential status, employment, and state expenditures for this population are captured through several large data centers or repositories such as those maintained by the U.S. Department of Education

(n.d.), U.S. Department of Labor (n.d.), the Residential Information Systems Project (RISP) (University of Minnesota, n.d.) , and the State of the States in Intellectual and Developmental Disabilities Project (University of Colorado, n.d.). Noticeably absent, however, are data that focus on their health, leading to the observation that “health is the last frontier” for people with IDD.

Agencies at both the federal and state levels need robust and reliable data to inform planning in areas such as budgets, programs, policies, and performance evaluation. Data are needed to assist federal and state agencies in addressing questions like the following:

Fiscal projections. What are the decadal projections for expenditures? What is the known prevalence of people with IDD who are potential beneficiaries? What is their anticipated life expectancy? How do changing demographics of aging parents and family members who have served as informal caregivers affect projections for services?

Program planning. What is the status of services and service delivery systems? What is known about workforce availability and what are anticipated training needs? What determinants of health represent future health risks to beneficiaries? What emerging technological advances may impact program needs and resources?

Policy planning. Are agencies serving the right people, and all of the right people? Are they providing the right services? What contextual and technological changes need to be addressed through policy?

Performance evaluation. What impact do agency services have on the health of people with IDD? Can better monitoring of needs and outcomes provide evaluation data that demonstrate the relative value of programs or policies?

In 2016, when the Administration on Intellectual and Developmental Disabilities was seeking current information on prevalence of IDD for their planning purposes, the most recent prevalence data for adults was the National Health Interview Survey Disability Supplement of 1994-95 (NHIS-D 1994-95). Much has changed for people with IDD in the subsequent 25 years in longevity, place of residence, health care, and participation in their communities. NHIS-D of 1994-95 data are regarded as much too dated to be used in policy planning for fiscal projections or goal setting such as Healthy People 2030. HHS initiatives require accurate current prevalence estimates to ensure getting the right services to the right people, and more accurate prevalence projections to support planning for aging services as more people with IDD age into eligibility. In a Summit convened by the Administration on Community Living in November of 2017, representatives from six DHHS federal agencies described their current efforts as “cobbling together” information from multiple sources, including the NHIS, to address their data needs as best they could.

Need for Health Surveillance Data

Inadequate health surveillance of people with IDD hampers our understanding of their health status, health determinants, and health needs. Surveillance is used by public health to track the incidence and prevalence of target populations, as well as to identify characteristics that can influence or contribute to their health (Fox, Bonardi, Krahn, 2015). In previous decades, many Western countries placed people with IDD in institutions. Because national surveys typically do not include institutionalized populations, such as people in adult correctional facilities, juvenile facilities, skilled-nursing facilities, and other

institutional facilities (e.g., mental hospitals and in-patient hospice facilities), people with IDD were not included in national health surveillance.

More people with IDD now live in their communities, yet they are still at risk of being “invisible” in many data surveillance systems. There are at least two reasons for this: a) failure to be able to identify respondents with IDD within the larger respondent data set; and b) sampling frames that do not take into account the unique residential characteristics of many people with IDD. Without identifier questions that allow for ready identification of respondents who meet criteria for IDD, their data cannot be identified for analyses specific to this group. Further, it is unclear that population sampling methods adequately represent those people with IDD who live in group homes, where group homes may not be considered “households” and where density of disabilities is greater than expected by normal distribution. Findings from Magana and colleagues (2016) suggest that national health surveillance only identifies about 60% of community-dwelling adults with IDD.

Need for more complete health information

The information gathered through general health surveillance is not sufficient. The health conditions of people with IDD are often more complex than the general population, and their life circumstances, such as residential settings, may present unique challenges to understanding environmental contributors to health. General health surveillance systems typically do not address those factors that are unique to the health status, determinants, and needs of people with IDD. Examples of needs for other data types include administrative data, in-depth clinical studies of issues unique to persons with IDD,

longitudinal studies to determine health trajectories across the lifespan, direct support providers and caregiver needs, and provider competence and availability.

Costly population

Despite this relative lack of knowledge on the health status of people with IDD, we know that their care is expensive. Although studies vary in how cost estimates are calculated, they all indicate that the economic costs for persons with IDD are substantially higher than persons without disabilities. Estimates of cost vary depending on type of services included in the calculations, year of estimates in U.S. dollars, and country of study. In 2006, national health care expenditures associated with all disabilities were estimated at \$400 billion. Public dollars paid for 70% of these costs through Medicaid and Medicare, and the largest costs were associated with people in institutions (Anderson, Wiener, Finkelstein, & Armour, 2011). Per person cost of care across the lifespan in the U.S. and the U.K. for persons with autism spectrum disorder and intellectual disability (ID) was estimated at \$2.4 million for the U.S. and \$2.2 million for the U.K. in U.S. dollars (Buescher, Cidav, Knapp, & Mandall, 2014). These estimates were based on syntheses of previous studies and considered costs associated with accommodation, medical and nonmedical services, special education, employment support, and productivity loss for the individual and family. An earlier per person economic cost estimate for persons with ID used different methods that included direct medical, direct non-medical, and lost productivity cost. Those estimates were \$870,000 for ID and \$800,000 for cerebral palsy in 2000 U.S. dollars (Honeycutt, Gross, Dunlap, Schendel, Chen, Brann & Homs, 2003), or about \$1.16 and \$1.07 million in 2012 U.S. dollars respectively.

Served vs unserved population

A major concern in health surveillance of people with IDD is whether the study includes the full population—both people receiving services as well as people not known to service systems. This is also referred to as including the unserved as well as the served population. Many estimates, including prevalence estimates, are limited to a specific service delivery system in terms of who is included in the sampling frame. We know a fair amount about people receiving developmental disability services through data collected by the National Core Indicators and state administrative programs. However, the group served through developmental disability services is estimated to include only about 20% of the IDD population (University of Minnesota, RISP, 2016), leaving many questions unanswered about people not included in services. We are now seeing the emerging use of other administrative data sources such as Medicaid and Medicare to identify this population and better understand their health needs (see McDermott, Royer, Cope, Lindgren, Momany, Lee...Armour, 2018; Haile & Reichard, 2019, this issue). A special issue of *International Review of Research in Developmental Disabilities* presented numerous illustrations on the use of secondary datasets to understand people with developmental disabilities (DD) and their families (Urbano, 2013). The catchment of these administrative sets includes a larger proportion of the population with IDD.

Who are People with Intellectual and Developmental Disabilities?

Variability in definitions

Different definitions of IDD are used across different countries, service agencies, and surveillance systems. Definitions vary in degree of severity of the limitation, whether they are based on medical diagnoses or on functional limitations in areas of major life activity, and whether ID is included as a type of developmental disability or considered distinct. Though these differing definitions can cause confusion, they are likely necessary to accommodate different purposes of data collection (Altman, 2011; Altman, Madans & Weeks, 2017). Intended use of the data drives selection of the unit of analysis (e.g., person vs diagnosis) as well as influences the severity of condition to be included. Typically, definitions of disability are more inclusive if they are intended to assure rights as protected by the Americans with Disabilities Act; and are more restrictive when used in determining eligibility for services.

Commonly used definitions

The most widely recognized definition of intellectual disabilities in the U.S. characterizes ID as significant limitations in both intellectual functioning and adaptive behavior that are evident before the age of 18 (AAIDD, 2010). The Developmental Disabilities and Bill of Rights Act of 2000 defines “developmental disability” as: a severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual attains age 22; is likely to continue indefinitely; results in substantial functional limitations in 3 or more of the following areas of major life activity: (1) self-care, (2) receptive and expressive language, (3) learning, (4) mobility, (5) self-direction, (6) capacity for independent living, (7) economic self-sufficiency; and, reflects the individual’s need for a

combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated. For children birth to 9, the 2000 law allows use of the “developmental disability” definition without meeting 3 or more of the above criteria if the individual, without services and supports, has a high probability of meeting these criteria later in life (42 U.S.C. §15001 et seq.). This is a restrictive definition of developmental disability, requiring significant limitations across multiple life areas.

Changing views of disability

Our views of disability and IDD continue to change, and they influence how we count and what we measure. For example, a view of disability based on the International Classification of Function, Disability and Health (WHO, 2001) places emphasis on the interaction of the person’s limitations with their environment, calling for closer consideration of the context in which people live and function to understand disability. Another example is that our understanding of autism disorders has changed significantly over the past two decades. This has resulted in substantially larger numbers of people now diagnosed with autism, generating questions about overlap with IDD. In 2003, Fujiura and Taylor warned that striving for a completely accurate measurement of ID may prove futile because ID operates as a “dynamic construct with multiple possible operationalizations” (p. 273). This caveat appears as true now as it was 16 years ago.

What Do We Know about the Health of People with Intellectual and Developmental Disabilities?

Poorer health

In 2002, the U.S. Surgeon General's report, *Closing the Gap: A National Blue-Print for Improving the Health of Individuals with Mental Retardation* (USDHHS, Office of the Surgeon General, 2002) brought significant public attention to the poor health of people with IDD. Since then, multiple studies have confirmed that, as a group, adults with IDD experience substantially poorer health outcomes than adults without IDD (e.g., Anderson, Humphries, McDermott, Marks, Sisirak & Larson, 2013; Krahn & Fox 2014). Compared with peers of a similar age, they are more likely to live with more complex health conditions (Evenhuis, 2011; Krahn, Hammond, & Turner A, 2006; Reichard, Stolzle & Fox, 2011), have limited access to appropriate health care and health promotion programs (Hayden, Kim, & DePaepe, 2005; Parish & Saville, 2003; Salvador-Carulla & Symonds, 2016), live with undetected vision and hearing loss (Woodhouse, Adler, & Duignan, 2004), and experience mental health problems with potential overuse of psychotropic medications (e.g., Bartlo & Klein, 2011; Emerson, 2011; Holden & Gitlesen, 2004; Lewis, Leake, King, & Lindemann, 2002). Recent attention to the intersectionality of race and ethnicity with disability demonstrates that health disparities are magnified for people who are both from a diverse race or ethnicity and have IDD (Magana et al, 2016; Yee et al, 2016).

Greater risk for chronic conditions

Because chronic conditions contribute significantly to mortality and cost of health care, they have received specific attention in the research literature. People with IDD typically are found to have higher rates of chronic conditions such as cardiovascular disease, diabetes, arthritis and hypertension (e.g., Balogh, Brownell, Ouellette-Kuntz, &

Colantonio, 2010; Balogh, Lake, Lin, Wilton, & Lunskey, 2015; Dixon-Ibarra & Horner-Johnson, 2014; Haverkamp, Scanlon & Roth, 2004; McDermott, Moran, Platt, Wood, Isaac, Dasari & MacLean, 2005; Reichard & Stolz, 2011). Cardiovascular disease is a leading cause of mortality in people with IDD (Draheim, 2006; deWinter, van den Berge, Schoufour, Oppewal & Evenhuis, 2016), as it is in the general population. More recent data demonstrates that people with IDD also experience mental health conditions such as schizophrenia and other psychotic disorders at alarmingly high rates (Haile & Reichard, 2019, this issue).

What Types of Health Data are Needed to Inform Projections, Program and Policy Planning?

Different types of data provide complementary information on the health of people with IDD, with multiple types of data needed to portray their health fully. These data types vary in terms of what they measure and how they measure. If the intent is to demonstrate differences between groups of people, such as utilizing a disparities framework, then it is critical to use measures that are relevant to and measured across different groups for comparison.

Health indicators

Indicators are key variables selected to be representative of a larger subset of potential variables to assess health and determinants of health (IOM, 2009; Walsh, 2008). Ideally, health indicators are measured reliably, relevant to populations, and sensitive to change. The National Core Indicators (NCI) exemplifies this approach, with its subset of

questions relating to health and health determinants (National Core Indicators, n. d.). The Pomona project, a multi-country European study to assess health of persons with IDD, also used a health indicators approach (Walsh, Kerr, Van Schroeijentstein Lantman-de Valk, 2003; Walsh, 2008). Krahn and colleagues (2010) presented a cross-walk of specific health indicators, comparing indicators recommended by the U.S. Institute of Medicine for the general population (2009) with those used by NCI and by the Pomona project for intellectual and developmental disability populations. Categories of indicators common to all data sources included mortality, health-related quality of life, condition-specific outcomes, health-related behaviors, health systems. Social and physical environments were included in the Pomona project and NCI but not IOM.

Disability specific variables

Health indicators can be supplemented with variables that are uniquely relevant to persons with IDD. The National Health Interview–Disability Supplement of 1994-95 is perhaps the best example of this approach for disability groups. The NHIS-D (1994/95) gathered in-depth information on issues of specific relevance to people with disabilities. In the ensuing 25 years, more than 200 studies used the NHIS-D data to investigate health and health determinants of people with disabilities (Ward, Ridolfo, Creamer, & Gray, 2015).

Types of health data

Figure 1 portrays different types of data that can be used to describe the health of groups of people. Recognizing these different data types provides a basis for understanding why statistics coming from different studies can be variable and confusing.

For all data types, the questions need to be asked “whom does this data represent?” and “who is missing?”

Insert Figure 1 about Here

Surveillance data

Surveillance has been defined as the ongoing systematic collection, analysis, and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know (Thacker & Berkelman, 1988). Surveillance data are collected from samples that are believed to represent entire populations. The sampling frames are examined closely to determine who might be missing—who might not have the opportunity to participate (e.g., institutionalized groups, homeless people, others). Surveillance is the only way to determine prevalence of a condition, drawing on a nationally representative sample. This allows the estimation of the total number of people in a population, such as total number of children and adults with IDD in the U.S. population.

Public health entities hold the authority to authorize and collect data following prescribed protocols for human subject protections (CDC, USDHHS, 2010). In these ways, surveillance is distinct from research. The decision to commit public funds to surveillance for a specific topic may be influenced by its relative frequency, ability to intervene or change an outcome, cost and severity of the condition, or public concern (Thacker & Berkelman, 1988). Repeat administration of the same or highly similar survey—repeat

cross-sectional data—allows researchers to track changes in a condition (e.g., changing prevalence rates over time) or in health indicators (e.g., effect of policy changes on outcomes). Repeat administration also allows researchers to pool data across multiple years to identify a sufficiently large sample size for subgroup analyses not possible with a single administration.

The numerous challenges to conducting health surveillance of people with IDD include determining whom to include (case definition), how to find cases, and how to obtain accurate information. A relatively low prevalence of IDD in the general population and the fact that most health surveys in the U.S., including the National Health Interview Survey, exclude institutionalized populations, create further difficulties. Larson and colleagues (2001) estimated that about 6% of people with IDD were living in institutional settings in 1994-95 and, therefore, would not be included in typical surveillance. Findings from others (Fujiura & Taylor, 2003) suggest that people with milder IDD may also be missed in national surveillance efforts—they may be included in the respondent pool but not be identified as having IDD.

Bonardi and colleagues (2011) conducted a critical review of almost 70 data sources to develop a compendium of health data sources for adults with intellectual disabilities. The compendium includes a chart that serves as a quick reference to compare across potential health surveillance sources (Bonardi, Lauer, Noblett, Taub, & Bershadsky, , 2011). NHIS data figure prominently in this listing.

Panel data or longitudinal data

Also referred to as panel data, longitudinal approaches track the same sample of respondents at different points in time. These samples can comprise individuals, households, establishments or other units. By tracking the same individuals over time, longitudinal data allow researchers to assess the “natural history” of persons with a specified condition or life circumstance. An example of a panel design with a nationally representative sample is the Medical Expenditure Panel Survey (MEPS). It follows the same households, tracking the same participants for five rounds of data collection over two calendar years, with overlapping panels across cohorts. The MEPS sampling frame is drawn from respondents to the National Health Interview Survey (NHIS). An example of longitudinal data that is not known to be nationally representative is the Model System networks sponsored by the National Institute on Disability, Independent Living and Rehabilitation Research. These Centers create national databases of people with specified conditions (e.g., spinal cord injury, traumatic brain injury, burns) as identified by participating projects, and follow these samples over time. Longitudinal panel studies require maintaining connection with the same individuals over time as their contact information changes, and require researchers to consider potential biases in retention of participants in the database. In contrast, repeated cross-sectional data described above provide trend data by giving the same survey to different samples over time.

Clinical data

Much of the information that we have on the health of people with IDD comes from studies with clinical or convenience samples. These data come from samples that have been identified through clinical populations, outreach recruitment strategies, or in other ways

that introduce bias into the sample. In this regard, they may be representative of other clinical samples, but are not known to be representative of the entire population of people with IDD.

Administrative data

Health services research is the multidisciplinary investigation of how social factors, financing systems, organizational structures and processes, health technologies and personal behaviors affect access to care, quality and cost of health care, and ultimately health and well-being (Lohr & Steinwachs, 2002). It includes analyses of entire health systems to understand utilization patterns and outcomes for the population of enrollees in that system. Disability researchers are making increasing use of various types of administrative data sets (see Bonardi et al., this issue). Iezzoni (2002) in the U.S. and Lin and colleagues (e.g., 2003, 2004) in Taiwan were early users of this method to demonstrate patterns in health care access and outcomes for people with disabilities.

Since 1991, the Metropolitan Atlanta Developmental Disabilities Surveillance Program has reviewed administrative records of 8 year olds to estimate the number of children with diagnosed DD in the metropolitan Atlanta area and related characteristics. Initially addressing four specific DDs (cerebral palsy, ID, hearing loss, vision impairment) and adding autism in 1996, trained abstractors compile data across health and education administrative data sources.

More recently developed methods link data across multiple administrative data sources. Increasing standardization on minimum data sets of administrative data allows for greater linkage across data sets to answer new questions. These methods may protect

confidentiality and allow for collecting pieces of information on the same person or family from different data sources. Two international examples of such data linkage across administrative data sets are described in the paper by Balogh, Lennard and colleagues (2019, this issue). In the U.S., Landes (2017a, 2017b) linked NHIS data with mortality life files to investigate changing patterns in the association between education and mortality for adults with IDD over eight decades.

Condition registries

Registries are established for specific conditions or diseases, in order to compile core information on people with target conditions. These registries are typically voluntary and, for that reason, are not representative of the entire population. Examples of condition registries are TREAT-NMD for neuromuscular diseases, DS-Connect for Down syndrome, and the National Spina Bifida Patient Registry.

Incident reporting

The systematic reporting and analysis of critical incidents is used to identify ways to prevent similar incidents. A familiar incident reporting system is the fatality review process conducted after deaths of individuals in care, such as children or adults with IDD. Since 1995, the U.S. Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) has mandated hospital-based surveillance of the “unexpected occurrence involving death or serious physical or psychological injury, or the risk thereof” (Wald & Shojanian, n.d.). In the U.K., the report of deaths among people with learning disabilities (comparable to U.S. term of ID) instigated closer examination of their deaths and of the health needs of people

with learning disabilities. The report *Confidential Inquiry into Premature Deaths of People with Learning Disabilities* summarizes the health and social care needs of this population (Heslop, Blair, Fleming, Hoghton, Marriott, & Russ, 2013). In the U.S., data from the Protection and Advocacy for Individuals with Developmental Disabilities network could potentially serve as a form of incident reporting.

What is the Prevalence of Intellectual and Developmental Disabilities?

AIDD currently uses an estimated prevalence of IDD as 1.58% of the general population, based on the definition and data collection methods of the National Health Interview Survey—Disability Supplement of 1994/95 and supported by the analyses of Larson and her colleagues (2001). This includes estimates for ID combined with DD. A recalculation of NHIS-D data that uses the revised criteria of the Developmental Disabilities Act of 2000, specifically the expanded eligibility for children aged 9 years and younger, yielded an estimate of 1.90% for IDD (cited by Larson, S.A., Eschenbacher, Anderson, Taylor, Pettingell, Hewitt, Sowers & Bourne, 2017). Meta-analyses across multiple countries have suggested rates for ID alone of about 1% (Maulik, et al, 2011; McKenzie, Milton, Smith & Ouellette-Kuntz, 2016). More recent estimates of ID for the general population in England approximates 2.5% (Hatton, Glover, Emerson & Brown, 2016) and 2003 estimates for Australia were as high as 3% (Australian Institute of Health and Welfare, 2008).

Estimates of prevalence of IDD show rates of DD among children to be variable and substantially higher than rates among adults. Rates for DD in children range from 6.99%

(Zablotsky, Black & Blumberg, 2017) to 16.24% when learning disabilities and attention deficit hyperactivity disorder are included (Boyle, Coulet, Schieve, Cohen, Blumberg, Yeargin-Allsopp, Visser & Kogan, 2011), with 13% of all children in U.S. public schools receiving special education services in 2015-16 (National Center for Health Statistics, 2018). This broad range of DD for children could relate to a number of methodological and conceptual differences in how the target population is defined and identified. These differences include whether identification is based on diagnoses or functional limitations, the range and number of DD assessed, and the data sources used (e.g., parental report, clinical/educational records, educational administrative data). In adults, estimates have relied on self-report in surveys (which requires that people are included in the sample and choose to self-identify) or use of administrative data for services (which requires meeting stringent criteria for service eligibility).

This drop-off in rates from children to adults has raised the concern that persons with IDD become “invisible” in adult data sets which leads to an underestimation of services needed. To examine this issue, researchers at the U.K. Learning Disabilities Observatory combined youth administrative data with census data and statistical forecasting to project prevalence rates of adults with profound multiple learning disabilities (PMLD) based on numbers of school children with special education needs associated with PMLD (Emerson & Glover, 2012). Larson and Anderson (2019, this issue) provide more detailed information in their systematic review of studies examining prevalence of IDD in children and adults.

What is the role of NHIS in health surveillance of people with intellectual and developmental disabilities?

National health Interview Survey

The National Health Interview Survey is the backbone of health surveillance in the U.S. Since 1957, NHIS has been used to monitor the health of the U.S. across a broad range of health topics collected through nationally representative household interviews. Results are used to track health status, health care access, and progress toward achieving national health objectives. While the sample of respondents is too small to provide reliable estimates at the state level, these estimates can be developed by pooling data across multiple years. Annual sample size is approximately 35,000 households containing about 87,500 individuals (Centers for Disease control and Prevention, n.d.a).

National Health Interview Survey—Disability Supplement (1994/95).

The Americans with Disabilities Act of 1990 prompted awareness of the need for better policy-relevant data on disabilities. Eleven federal agencies along with the Robert Wood Johnson Foundation collaboratively planned and funded the NHIS-Disability Supplement conducted in two phases in 1994 and 1995 (Centers for Disease control and Prevention, n.d.b). The NHIS-D provided invaluable health information on adults with disabilities and for children with disabilities and/or special health needs (Ward et al, 2015).

Recent research with NHIS on IDD

Since the special supplement on disability, the NHIS has continued to provide less specific but highly valuable information on the health of people with disabilities broadly.

Specific questions in the NHIS have been used to identify respondents with IDD. These identifier questions have been eliminated in the redesign of the NHIS for 2019.

A literature search identified the following topics on IDD using NHIS data: prevalence estimates and changing trends in prevalence over time (Boyle et al, 2011; Houtrow et al, 2014; Maenner et al, 2016; Pastor et al, 2012; Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015); prevalence and nature of co-existing conditions (Pastor & Reuben, 2009; Pulcini, Houtrow, Sargent, Shui, & Huhlthau, 2015; Schieve, Gonzalez, Boulet, Visser, Rice, Van Naarden Braun, & Boyle, 2012) and chronic medical conditions (Dixon-Ibarra et al, 2014); mortality (Landes, 2017a, 2017b); impact of race/ethnicity intersecting with IDD in relation to health disparities and access to care (Magana & Smith, 2008; Magana et al, 2016); and receipt of health care services (Bennett, McDermott, Mann & Hardin, 2017; Boulet, Boyle & Schieve, 2009; Boulet, Yanni, Creary & Olney, 2010; Parish et al, 2006). Other studies have examined health status of specific groups, such as children with Down syndrome (Schieve, Boulet, Boyle, Rasmussen & Schendel, 2009); or specific topics such as unhealthy weight in people with IDD (Phillips, Schieve, Visser, Boulet, Sharma, Kogan, Boyle, Yeargin-Allsopp, 2014; Yamaki, 2005); injury rates (Pastor & Reuben, 2006; Sinclair & Xiang, 2008; Xiang, Stallones, Chen, Hostetler & Kelleher, 2005); or economic costs (Lavelle, Weinstein, Newhouse, Munir, Kuhlthau & Porsser, 2014). NHIS data have also been used to examine the impact of parental disability on child's mental health (Neely-Barnes, Zanskas, Delabega & Evans, 2014) or characteristics such as birthweight influencing developmental outcomes (Boulet, Schieve & Bole, 2011). Still other studies have used Medical Expenditure Panel data that are based on the NHIS sampling frame to address similar questions for this population (e.g., Reichard et al, 2011; Reichard et al,

2011). The ID identifier of the NHIS has also been used to exclude respondents from other study samples in refining a population of interest (Iezzoni, Kurtz & Rao, 2016). Future research on health surveillance for people with IDD is threatened, however, by the elimination of those questions previously used to identify respondents with IDD.

Limitations of NHIS data for understanding health of people with intellectual and developmental disabilities

The NHIS data have been used successfully to estimate prevalence of people with IDD in non-institutional populations. These prevalence rates are underestimates, however, because institutional samples are excluded from the sampling plan. This appears to exclude persons in aggregate living facilities such as group homes if they are not considered residential addresses. If group homes are included, it is unclear whether the weighting for household members takes into account the greater density of disabilities in group homes. Further, information from NHIS is intended to be relevant for all populations and does not include questions more specific to persons with IDD, such as residential living situation, need for additional services and supports, and degree of limitations. The result is that data are aggregated across highly heterogeneous samples of people with IDD who vary greatly by severity, associated conditions, residential setting, needs for support or assistance and availability of services in their state.

While surveillance data are critically important, other types of data are also needed to inform program planning and policy. Such data types include longitudinal data that allow examination of the health trajectories of people with IDD over their life course. Early studies indicate substantive differences between people who age 'with' disabilities, and

those who age ‘into’ disabilities (e.g., Dixon-Ibarra, Krahn, Fredine, Cahill & Jenkins, 2016). Additional data needs include administrative data on service use, clinical studies for detailed information on select health conditions, and qualitative studies for a deeper understanding, including reports from the perspective of persons with IDD.

What Previous Work Informs Health Surveillance of People with Intellectual and Developmental Disabilities?

A number of previous efforts provide foundational information for the current initiative. They represent work by different entities with somewhat different populations: what they share is the desire to improve information at a population level on the health and health determinants of people with IDD.

Special Olympics Healthy Athletes

For more than two decades, Special Olympics has been collecting data through its free Healthy Athletes screenings for athletes participating in national and international events. With health screening data compiled over more than 1.6 million health examinations in countries around the world, the Healthy Athletes data represent the largest data resource for persons with IDD. Studies have reported on the Healthy Athletes screening data for oral health, obesity, vision, hearing, nutrition and health behaviors (e.g., Bainbridge, Arnold, Shellard & Tilley, 2015; Eisenbaum, DiNitto & Bishop-Fitzpatrick, 2018; Foley, Lloyd & Temple, 2014; Horowitz, Kerker, Ownes & Zigler, 2000). Because it samples only participating athletes and is voluntary, the dataset for Healthy Athletes is not representative of all people with IDD. Previous difficulties around individual identifiers in

the data further complicated its use in terms of eliminating redundant records and allowing longitudinal analyses. The Healthy Athletes data, however, have been highly valuable in bringing awareness of the health status and unmet health needs of people with IDD to the general public and governmental entities, as evidenced by the Surgeon General's report of 2001.

National Core Indicators (NCI). Initiated as a state-level quality assurance tool, NCI collects indicator information from a sample of people receiving developmental disability services from 46 states and the District of Columbia, although all states do not participate in all years. NCI Adult Survey captures information for people who are receiving long-term services and supports and has been used to explore programmatic and demographic issues. Reports have examined the use of psychotropic medications, health behaviors, access to primary health care, and have documented significant disparities in health and health care utilization compared to the general population (e.g., Havercamp & Scott, 2015). Its primary limitations are that its sample is limited to people receiving services, and questions persist about true randomization of the sample and adequate standardization of data collection. Proxy reporting is allowed for parts of the data set to ensure people who are not able to self-report are included.

CDC-sponsored studies on health surveillance of adults with intellectual and developmental disabilities

Beginning in 2009, CDC initiated a programmatic effort to determine promising approaches to improve health surveillance information on adults with IDD in the U.S. In collaboration with the Association of University Centers on Disabilities and the then

Administration on Developmental Disabilities, they convened a series of three meetings with researchers, advocates, and policy-makers to develop a framework for action (Krahn, Fox, Campbell, Ramon & Jesien, 2010) and supported a series of targeted studies to implement the steps of the framework. These steps include: (1) defining ID in ways that are clinically, functionally and operationally valid (Bonardi, Lauer, Mitra, Bershadsky, Taub & Noblett, 2011), (2) synthesizing a knowledge base including data sources and surveillance techniques, (Bonardi et al, 2011) (3) extending previous analyses of existing data sources to enhance knowledge and identify surveillance gaps, (4) piloting state or regional demonstrations of these strategies, especially administrative data and (5) determining sustainable approaches to expand health surveillance of people with IDD (Fox, Bonardi & Krahn, 2015).

CDC-sponsored multi-state Medicaid and intellectual and developmental disabilities project. This work of the National Center on Birth Defects and Developmental Disabilities at CDC has expanded to support researchers in ten states to identify persons with diagnoses of IDD (using ICD-9 or ICD-10 codes) to examine Medicaid or all-payer claims data. Findings from this series of studies are beginning to emerge. They have demonstrated the ability to identify beneficiaries with IDD across five states (McDermott, Royer, Cope, Lindgren, Momany, Lee,...Armour, 2018), to characterize emergency department visits in one state for ambulatory care sensitive conditions by persons with IDD (McDermott, Royer, Mann & Armour, 2018), and to develop an algorithm to identify persons with IDD in all-payer claims data in one state (Philips, Houtenville & Reichard, 2018). In the future, this line of research is intended to inform the development and

implementation of an evidence-based intervention to improve the health of people with intellectual disabilities.

AIDD led cross-agency initiative on prevalence and health surveillance. In November of 2017, the U.S. Administration on Intellectual and Developmental Disabilities hosted a meeting with representatives from other HHS agencies, national disability organizations, and researchers from eight universities. The Summit addressed agency needs for prevalence and health surveillance data on people with IDD, the potential role of the National Health Interview Survey to address those needs, and promising future approaches to health surveillance for people with IDD. As a result of these discussions, AIDD established two workgroups: the first to work with the National Center for Health Statistics to determine what would be needed to identify respondents with IDD in the NHIS (Haverkamp et al, 2019, this issue); the second to identify promising practices in examining state and local administrative data (Bonardi et al, 2019, this issue).

Summary and Next Steps

While people with IDD are a relatively small portion of the general population, they are of significant concern to a number of federal agencies because of heightened needs for services and supports to promote good health and integration in their communities. Comprehensive data on the prevalence and health needs are 25 years old, and surveillance data through the NHIS is being eliminated with the 2019 revision of that survey. In an era of data-driven decision-making, reliable prevalence and health surveillance data on this population is threatened more than ever. Robust and sustainable methods for data collection and analyses are critically needed to support agencies in fiscal projections,

program planning, policy development, and evaluation of programs and policies, and to provide researchers and advocates with data to monitor and understand health of this population.

Extending the work of the previous decade, new efforts are needed for improving health surveillance of people with IDD. The current data improvement initiative reflects continued collaboration across HHS agencies, and is being accomplished through public-private partnership across government, research, and advocacy entities. Two recommendations for actions in the short-term are 1) to continue cross-agency collaboration to develop and include questions for the NHIS and other surveys that will accurately identify respondents with IDD; 2) to support learning collaboratives that make greater use of state and local administrative data for more local planning. For the intermediate term, recommendations include increasing capacity for data linkage and analysis methods to better understand the health status and health risks of people with IDD. In the long term, it is recommended that HHS agencies implement new data collection studies using established methods such as multi-site longitudinal panels; and investigate new methods for data collection and synthesis to capitalize on the promise of sensor technology, data mining, and other emerging methods.

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Table 1. Prevalence of intellectual disability and developmental disabilities for children and adults across studies.

Study	Data Source	Estimates of ID and/or DD	Additional Notes
Child estimates			
Boyle et al., 2011	NHIS 1997-2008	15.04% for DD in 2008 (11.78% for 3-10 year olds; 16.24% for 11-17 year olds) 0.71% for ID across years	LD (7.66%), ADHD (6.69%) Rates higher in Medicaid population and with lower maternal education
Yang et al., 2016a	OMAS 2015 children	4.6% for DD 18 and younger ID not measured separately	Medicaid population 20.3% children with special health care needs but not DD
Zablotsky et al., 2015	NHIS (2011-2014)	5.75% for any condition 1.27-1.10% for ID 4.84-3.57% for Other DD 1.25-2.24% for ASD	Change in order of questions of 2014 does not change overall DD rates or ID rates, but decreases other DD and increases ASD
Maenner et al., 2016	NHIS and NSCH	1.21 and 1.22 for ID .026 and .029 for CP	Highly comparable findings for NHIS 2011-13 and NSCH 2011-2012
Braun et al., 2015	MADDSP 1991-2010 Record review	1.06-1.36% for ID (1991,2010) .042% to 1.55% for ASD (1996 to 2010) CP, HL, VI relatively stable	Record review of 8 year olds
Adult Estimates			
Larson et al., 2001	NHIS-Disability supplement 1994/95	1.49-1.58% MR/DD overall 3.84% children birth to 5 3.17% youth 6-17 0.79% for 18 and older	Identification of MR by self/proxy report as cause of functional limitations, or related condition with significant learning limitation

Maulik et al., 2011	Diverse data tools	1.036% overall across 52 studies	International Meta-analysis— Children/youth> adults Low/Middle Income countries> High income
Yang et al., 2016b	OMAS 2015 adults	4.1% for DD ID not measured separately	Medicaid population; In response to the question: “do you have a DD?”
McKenzie et al., 2016	International meta-analysis	~1% for ID Range .05-1.55%	Diverse methods for estimating prevalence across studies
Larson et al., 2017 citing Larson 2015	NHIS-Disability supplement 1994/95	1.9% overall	Recalculation of NHIS-D rates using expanded criteria for child eligibility from DD Act of 2000

Note: ID = Intellectual Disability; DD = Developmental Disabilities; ASD = Autism Spectrum Disorder; CP = Cerebral Palsy; HL = Hearing Loss; VI = Vision Impairment; MR/DD = Mental Retardation/ Developmental Disabilities
 NHIS = National Health Interview Survey; NSCH = National Survey of Children’s Health; MADDSP = Metropolitan Atlanta Developmental Disabilities Surveillance Program; OMAS = Ohio Medicaid Assessment Survey

Call for Better Data on Health of People with IDD

Figure 1. Types of data used for health assessment and monitoring

