

## **What matters in population health and how we count it among people with intellectual and developmental disabilities: Introduction**

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*“We are invisible in the data. We can’t make people believe we need more services if we don’t have data to back us up.”*

*U.S. Surgeon General’s Report, Closing the Gap, 2002.*

This issue, *On Counting What Matters: Finding Adults with Intellectual and Developmental Disabilities in Population Health Data*, presents an overview of health surveillance research for people with intellectual and developmental disabilities (IDD) in the U.S. While public health now conducts surveillance of people with broadly defined disabilities and compares their health status with that of individuals without disabilities, there are many challenges in conducting health surveillance of people with IDD. Difficulties include how to define cases, how to find cases, and how to obtain accurate information (Krahn, Fox, Campbell, Ramon, & Jesien, 2010).

This issue will present critical conceptual and methodological issues, including recent prevalence and population health analyses, along with proposals that can lead to more equitable health and improved health surveillance for people with IDD.

This special issue of Intellectual and Developmental Disabilities emerged from almost two decades of work to improve data that can inform policy and practice at the federal and state levels. This work has involved collaborations across agencies within the Department of Health and Human Services, most notably the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC, the Administration on Intellectual and Developmental Disabilities (AIDD) at the Administration for Community Living, and the National Center for Health Statistics (NCHS) at CDC. Leaders at these federal agencies have partnered with

university researchers and advocacy organizations to identify and overcome the IDD health surveillance challenges. Earlier work built on the Surgeon General's report of 2002 (US HHS, 2002) and resulted in an initial multi-step plan for advancing the work (Krahn, et al, 2010). The most recent impetus for this work came from a Summit and subsequent workgroups hosted by AIDD in 2017-2019 to examine the status of health surveillance and people with IDD.

Health surveillance informs policy and practice through the systematic and ongoing collection, analysis, and interpretation of data on target populations. While health surveillance has generally improved in the U.S., including for people with disabilities broadly, health surveillance of people with IDD has always been sparse, and has diminished to the point that national surveillance data is virtually non-existent in 2019. This paper establishes a foundation for the papers to follow and frame several themes that weave throughout this issue on health surveillance. We provide a brief historical and legislative context, discuss key issues in defining IDD, and highlight the need to analyze health disparities in people with IDD that considers factors such as race, ethnicity, and disparities that may be revealed relative to the larger population.

### **Historical and Legislative Context for IDD in the U.S.**

While people with IDD have always been part of American society, advocacy efforts beginning in the early 1960s brought increased national attention to their reduced health status and social isolation (Braddock & Parish, 2001; Bersani & Lyman, 2009). Since that time, the understanding of this population has continued to grow and change. Terminology has changed, diagnostic

practices have advanced, the nature of services and supports have evolved, and technology has altered many aspects of life. Indeed, our very understanding of the IDD construct has changed, along with increased societal expectations for richer, more participatory, and self-directed lives for people living with these conditions.

The U.S. federal government increased its protection of rights and provision of services for people with IDD over time. Changes in federal laws, enacted by Congress and interpreted by the U.S. Supreme Court, have impacted the concept of disability through provision of services and protection of civil rights of people with disabilities. The Developmental Disabilities Assistance and Bill of Rights Act (DD Act; P.L. 106-402) was first enacted in 1963 to support research, training, protection and advocacy, and to test innovative service delivery models for people with IDD. In 1965, the Medicaid program was first introduced, expanding Kerr-Miles federal funding through a partnership with states to provide services to certain low-income people, including some people with disabilities (Title XIX of the Social Security Act). Subsequently in 1971, optional Medicaid-funded Intermediate Care Facilities for Individuals with Intellectual Disability (ICF-ID, previously ICF/MR) spurred state investments to reduce overcrowding in larger institutions and provide active treatment for people with IDD in facilities with four or more residents (Title XIX of the Social Security Act). The Rehabilitation Act of 1973 (Pub.L. 93-112, 87 Stat. 355) provided additional protections for people with disabilities from discrimination in

federally-funded services. The Education for all Handicapped Children law (20 U.S.C, § 1400 et seq), passed in 1975, guaranteed a free and appropriate public education for all students regardless of the type or severity of disability. In 1981, Congress passed a law (section 1915 of the Social Security Act) permitting states to expand services in community-based settings through Medicaid Home and Community Based Services (HCBS) waivers. In 1990, Congress endorsed the importance of participation in society for individuals with disabilities when it enacted the Americans with Disabilities Act (ADA; Pub.L. 110-325). The ADA established disability civil rights by mandating reasonable accommodations to enable full participation in society for people with disabilities. In June 1999, the U.S. Supreme Court further clarified the ADA in its *Olmstead v. L.C.* decision concerning the right of people to live and participate in community-based settings (527 U.S. 581). The Affordable Care Act, passed in 2012, prohibited health insurance discrimination based on health status or disability (Pub.L. 111-148). More recent legislation can be found at <https://rootedinrights.org/history-of-disability-rights-interactive-timeline-text-only/>. As the above legislations have been reauthorized and updated by Congress, and public policies have changed to promote community living, there has been widespread downsizing or closure of publicly-funded institutions and a corresponding growth of community-based services for people with IDD.

### **The Data Conundrum**

National health surveys are used to track the incidence and prevalence of populations of interest, as well as to identify characteristics that can influence or contribute to their health. The Affordable Care Act required establishing minimum data collection standards for disability status as well as for race, ethnicity, sex, and primary language in all national population health surveys. This requirement was intended to ensure that these marginalized groups were identifiable through expanded surveillance and were more adequately represented in analyses of population data. The minimum data standard on disability status is a six-item question set that assesses functional limitation in hearing, vision, cognition (concentrating, remembering or making decisions), mobility, self-care, and doing errands alone (U.S. Department of Health and Human Services, 2011). Unfortunately, these questions do not allow for identification of people with IDD within the disability group.

Timely and reliable data is essential to identify health disparities, understand the causes and correlates of disparities, and to monitor progress in reducing them. Recent changes to two national surveillance systems (National Health Interview Survey and the Survey on Income and Program Participation) eliminated items that had been used to identify adults with IDD. Without specific questions that allow for ready identification of respondents with IDD, this population becomes invisible in the data. Inadequate health surveillance of people with IDD hampers our understanding of their health status, health determinants, and health needs.

Health surveillance among people with IDD presents several challenges . The first barrier relates to “caseness” and operationally defining what is meant by IDD. There is substantial variability

across the conceptual and operational definitions of IDD (Bonardi et al. 2011; Krahn, Fox, Campbell, Ramon, & Jesien, 2010). These differing definitions lead to differing prevalence estimates, and likely contributes to non-overlapping groups of people in survey samples. This is illustrated by examining prevalence of IDD in children. When conditions such as learning disability (LD) and attention deficit hyperactivity disorder (ADHD) are included in estimates, up to 16% of children are identified as having IDD (Boyle, et al, 2011), or approximately 1 in 6 children (CDC, n.d.). When LD and ADHD are not included, the estimated prevalence is typically around 6-7% (Zablotsky, Black & Blumberg, 2017; Anderson, Anderson, Larson, MapleLentz, Hall-Lande, this issue). Improved IDD health surveillance will depend upon disability researchers coming to greater consensus on IDD definitions and terminology.

A second major challenge is *finding* people with IDD in national surveys. The current national surveillance systems do not allow for identification of respondents with IDD. The newly established HHS minimum standards (US HHS, 2011) do not allow for ready identification of people with IDD within the disability group. A minimum set of items to identify respondents with IDD will need to be developed, tested, and added to national surveys.

Administrative data has been leveraged for IDD health surveillance (see Bonardi et al, this issue); however this approach has its own limitations and challenges (e.g., Krahn, Fox, Campbell, Ramon, & Jesien, 2010). Because the vast majority of people with IDD live with their families and do not receive any financial or programmatic support for their disability (see Bonardi, Krahn, Fay, & Lulinski, this volume), administrative data from DD Services is incomplete. By estimate, only about 20% of people with IDD were known to state IDD agencies



and only 17% received Medicaid or state funded long term services and supports in 1994-95 (Larson et al, 2018). While administrative data offers opportunities to understand the characteristics and needs of current service recipients with IDD, this approach is limited to only those served. Data based on the broader U.S. population are needed to fully count the IDD population as well as to understand their health status, health outcomes, and health disparities.

### **Conceptualizations of Disability**

The concept of disability has evolved over the past century (Iezzoni & Freedman, 2008; Leonardi, Bickenback, Bedirhan Ustun, Kostanjsek & Chatterji, 2006; Lollar & Crews, 2003), with changing conceptualizations reflected in changing definitions in federal statutes. During much of the 20<sup>th</sup> century, experts viewed IDD within a medical model as a health problem arising directly from disease, trauma, or medical condition. Health problems were thought to reside within or be a trait of the individual and to result directly in the individual's inability to function (Areheart, 2008; Iezzoni & Freedman, 2008; Shakespeare, 2006). The use of diagnostic categories to classify disabilities is founded in the medical model.

The independent living and civil rights movements focused attention on external forces such as social and environmental circumstances in determining the limitations a person experiences (Brisenden, 1986). The social model views disability as a condition resulting from the demands or expectations of the social environment, including how one's society is organized and the physical and attitudinal barriers of prejudice and discrimination one experiences (Mont, 2007; Oliver, 2013; Shakespeare, 2006). The social model of disability views social policies as the

solution to disability, particularly policies that direct changes to environments, prevent discrimination and exclusion, and increase opportunities for participation. Influenced by this emphasis on a social model, a committee of the World Health Organization (WHO) worked for more than two decades to define disability in a framework that integrated these differing conceptualizations (Pope & Tarlov, 1991). The most recent version, the International Classification of Functioning, Disability and Health (WHO, 2001), was endorsed by all 191 member states. The ICF presents a view of disability as “a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives,” and as such asserts that “[o]vercoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers” (WHO, 2011).

### ***Defining Disability***

As documented by the Interagency Committee on Disability Research (ICDR), definitions of disability and the criteria used to meet disability determinations vary widely across federal agencies, particularly among those definitions related to program eligibility (CESSI, 2009). Definitions for the purpose of extending civil rights protections tend to be broad. For example, the Americans with Disabilities Act defines disability as “a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment.” (42 U.S.C. § 12102 (1)). As civil rights legislation, the ADA defines disability broadly to encompass physical and mental impairments to prohibit discrimination against people with disabilities. In contrast, definitions established to determine eligibility for services tend to be more narrow and elastic depending on the circumstances and sometimes state or program budgets. The criteria of

the Social Security Administration reflect a narrower definition, as does the definition of developmental disability in the Developmental Disabilities Assistance and Bill of Rights Act (DD Act). Another factor explaining definitional differences relates to the point in time when the definition was created. Conceptual understandings and historical contexts contribute to definitions. While identification of disability historically relied heavily on diagnostic criteria using coding systems such as the International Classification of Diseases and the Diagnostic and Statistical Manual, more recent developments place greater emphasis on functional limitations (Lollar & Simeonsson, 2005). Our understanding of developmental disabilities has changed substantially over the past half-century, and we are increasingly aware of other characteristics in addition to IDD, such as race/ethnicity or poverty, that can influence diagnoses and can compound health impacts (see Goode, Carter-Pokras, Horner-Johnson, & Yee, 2014).

***Diagnostic versus functional approach.*** The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) describes neurodevelopmental disorders as a group of conditions with onset in the developmental period that are characterized by developmental deficits that produce impairments of personal, social, academic, or occupational functioning (American Psychiatric Association, 2013). Diagnoses are made in a clinical or educational setting, and typically provide information about the etiology of the condition, potential interventions, as well as anticipated prognosis. Surveillance studies of developmental disabilities by the CDC are often diagnostically based. For example, medical and educational records are reviewed to determine prevalence of diagnoses of conditions in the Metropolitan Atlanta study (e.g., Christensen, Braun, Baio, Bilder, et al., 2018; Van Naarden Braun, Christensen, Doernberg, Schieve, Rice, Wiggins & Schendel, 2015). The NHIS questions for child developmental disability are based

on parent reported diagnoses for conditions such as attention deficit hyperactivity disorder, intellectual disability, cerebral palsy, autism spectrum disorder, seizures, and other developmental delays in U.S. children (e.g., Boyle, Boulet, Schieve, Cohen, Blumberg, Yeargin-Allsopp, 2011; Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). The diagnostic-based approach to defining developmental disabilities presents both advantages and disadvantages for surveillance research. An advantage for public health researchers is that establishing the presence of a developmental disability can be achieved with individual items (e.g., “Does your child have intellectual disability?”). Numerous studies based on medical claims data rely on identification by diagnostic codes (e.g., McDermott, Royer, Cope, Lindgren, Momany, Lee ... & Armour, 2018; Haile et al, this issue). However, diagnosis may reveal little about severity and functional characteristics of the individual. In fact, Lollar and Simeonsson (2005) observed that characteristics among people with the same diagnosis may differ more than those between people with different diagnoses. Diagnosis-based prevalence estimates are also influenced by access to the health care and educational services needed to receive a diagnosis.

A functional approach to defining and describing disability was adopted by the World Health Organization in the International Classification of Functioning, Disability, and Health (ICF; WHO, 2001), by the American Association of Intellectual and Developmental Disability (AAIDD) in the intellectual disability terminology and classification manual (Schalock, 2010); and in the Developmental Disabilities Act circa 2000. In surveillance, a functional approach requires that persons or their proxy reporters endorse limitations across a range of areas of functioning. The NHIS questions on disability for adults generally are function-based (e.g., “Because of a health problem, do you have difficulty remembering or concentrating?”). Because

these definitions require significant functional limitations, they exclude some people who are not severely limited by their condition.

*Definitions influencing the relationship of ID and DD.* The AAIDD definition of ID (Schalock et al, 2010) is based on significant limitations in intellectual functioning and adaptive behavior. Intellectual disability is often regarded as a type of developmental disability. However, when the DD Act definition of developmental disability is used, it requires significant limitations in at least three areas of functioning. Using this definition, persons may have intellectual disability as defined by AAIDD but not meet criteria for DD. This was the case for 34% of the NHIS-D 1994-1995 population identified with IDD (Larson et al, 2001).

### **Capturing the Whole Population: Race, Ethnicity, and People in US Territories**

Rooted in the U.S. social fabric are the cultural views and biases, both implicit and explicit, regarding people with IDD. Racial and ethnic biases in the U.S. have additionally impacted how people with disabilities from minority backgrounds are diagnosed (Fish, 2002). Such biases are apparent in the overrepresentation in special education programs of African American children and Latino children with limited English proficiency. In addition, a complex array of dynamics further contributes to a pattern of disparities in health, education, and employment. These include, but are not limited to, stereotyping, conscious and unconscious biases, culturally-biased assessment instruments and practices, institutional and structural racism, and the debilitating effects of living in marginalized and disadvantaged families and communities (Goode, Jones, Christopher, & Brown, 2017). These issues are among those targeted by current efforts to address health equity within HHS (US HHS Office of Minority Health, 2013).

Title VI of the Civil Rights Act of 1964 states: “*No person in the United States shall, on the ground of race, color, or national origin be excluded from participation in, be denied the benefits of, or be otherwise subjected to discrimination under any program or activity receiving Federal financial assistance*” (Pub. L. No. 88-352 42 U.S.C. § 200d et seq.). This Act has implications for ensuring the inclusion of racially, ethnically, and linguistically diverse populations in surveys that are funded by the federal government. Moreover, beyond any statutory requirements, when any group is excluded from the survey, surveillance is incomplete and the unique needs of excluded groups can neither be identified nor met. Including diverse populations in surveys requires that the survey design adopt a sampling frame that intentionally includes these populations and, ideally, oversamples for underrepresented groups. It also requires that the construction of the items and instructions for the questionnaire are appropriate for diverse populations who reside in the U.S., its territories, and tribal communities. This includes but is not limited to individuals with disabilities, those who are not literate or have low literacy skills, and individuals who are Deaf or hard of hearing (Goode, Jones, Christopher & Brown, 2017; US HHS, 2014).

The *HHS Action Plan to Reduce Racial and Ethnic Health Disparities* (2011) provides guidance for reducing disparities in health and health care for diverse populations (HHS Action Plan to reduce Racial and Ethnic Health Disparities). Purposeful attention to cultural and linguistic differences is particularly important for people with IDD, given recent evidence of compounded health disparities at the intersection of disability, race, and ethnicity. These studies demonstrate important variability in health disparities by race and ethnicity for people with disabilities

(Horner-Johnson & Dobbertin, 2014; Onyeabor, 2016; Peterson-Besse, Walsh, Horner-Johnson, Goode, & Wheeler, 2014). As Goode et al. (2014) noted, health disparities research within racial, ethnic, and disability groups has typically failed to consider the “multiple cultural identities within population groups (p. 6).” As a result, there is a significant need for collaborative research to address health disparities where disability, race, and ethnicity intersect (Yee et al., 2018). The *National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care* (National CLAS standards; US HHS, 2001) outline standards and specify practices that are appropriate for culturally sensitive questionnaire design to maximize the comparability of survey questions across cultures and reduce measurement error related to question design.

### ***Data Collection in the Territories***

The understanding of a national level of IDD prevalence is further limited by the omission of the U.S. territories in the sampling frames of most national surveillance systems. Although Puerto Rico is included in the sampling frame for the Behavioral Risk Factor Surveillance Survey, American Community Survey, and Survey of Income and Program Participation, the omission of the other U.S. territories from most population-based surveys and the National Health Interview Survey (NHIS) limits the ability to estimate prevalence and understand health outcomes of all Americans with IDD.

## **Addressing the Data Conundrum**

The IDD data conundrum has received considerable attention. Prompted by Special Olympics International, a Surgeon General's series of listening sessions across the country resulted in the Surgeon General's *Closing the Gap report of 2002*. Subsequently, a series of summits and workshops were organized in 2009-2013 by CDC's National Center on Birth Defects and Developmental Disabilities in collaboration with the Association on University Centers on Disabilities and AIDD (e.g., Krahn, Fox, Campbell, Ramon, & Jesien, 2010). This work resulted in a five-step approach to national, comprehensive IDD health surveillance that include: (1) define IDD in ways that are clinically, functionally, and operationally valid; (2) synthesize the knowledge base; (3) extend analyses of existing data sources to identify gaps in IDD health surveillance; (4) pilot state or regional demonstrations; and (5) develop sustainable approaches to expand surveillance nationally. Fox, Bonardi, and Krahn (2015) described the considerable progress in advancing knowledge across the first four steps, leading to the need for approaches that are sustainable and comprehensive.

Building on earlier work to improve surveillance data on children and adults with IDD, and recognizing the challenges to collecting such information, the Administration on Intellectual and Developmental Disabilities (AIDD) initiated discussions in 2015 with a number of federal partners in HHS to explore potential solutions, including the use of NHIS. These discussions led AIDD to convene a multi-agency, multi-stakeholder meeting in November 2017 with representatives from a number of HHS agencies: Administration for Community Living (ACL), Assistant Secretary for Planning and Evaluation (ASPE), National Center for Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control & Prevention (CDC), Centers for Medicare & Medicaid Services (CMS), National Center for Health Statistics (NCHS)



at the CDC, and the HHS Office on Minority Health (OMH). It also included the following national disability organizations: Association of University Centers on Disabilities (AUCD), Center for Epidemiological Research for Individuals with Intellectual and Developmental Disabilities (CERIID), Human Services Research Institute (HSRI), National Association of Councils on Developmental Disabilities (NACDD), and National Association of State Directors of Developmental Disability Services (NASDDS); and a number of university-based disability researchers. Following the November 2017 meeting, two workgroups were established: (a) the National Health Surveillance Workgroup and (b) the State and Local Administrative Data Workgroup.

This renewed attention to improving health surveillance of people with IDD led to this special issue. The first three papers address the current state of affairs for IDD data in the U.S. This paper by Havercamp and Krahn outlines broad issues that comprise the “data conundrum.” The paper by Krahn provides a more in-depth look at a number of these issues and calls for improved data. Anderson, Larson, MapleLenz, & Hall-Lande summarize findings from a systematic literature review on prevalence estimates for IDD. The subsequent three papers describe emerging approaches for capitalizing on available methods. The paper by Havercamp and colleagues represent the work of AIDD’s workgroup on national surveillance. It examines the constructs of ID and DD, determines what core question set would be needed to identify respondents with ID and DD in the NHIS and other surveys. Bonardi and colleagues describe examples of best practices for gaining more and richer information from available state and multi-state administrative data sets. In the final paper in this section, Haile & Reichard use diagnostic codes to identify enrollees in a set of national Medicare data, describing findings for a

range of chronic conditions. The final set of papers anticipates future approaches. Balogh from Canada and Leonard from Australia describe data linkage centers in parts of their respective countries, demonstrating the infrastructure requirements and types of findings that can be obtained when administrative data from multiple service systems are linked. In anticipating future possibilities, Tassé and colleagues share a glimpse into the future of how technology may soon enrich our possibilities for improved information on health surveillance for people with IDD. The final paper briefly summarizes themes across the papers and offers ideas for future directions and strategies.

As editors of this special issue, we have learned much from the contributing authors, and are excited about the possibilities for improved data to inform programs, policies and practices. We hope that you as readers will have a similar experience as you learn about the work of your colleagues.

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