

**Identifying People with Intellectual and Developmental Disabilities  
in National Population Surveys**

Susan M. Havercamp, PhD  
Ohio State University Nisonger Center  
[Susan.havercamp@osumc.edu](mailto:Susan.havercamp@osumc.edu)

Gloria L. Krahn, PhD, MPH  
Oregon State University  
[Gloria.Krahn@oregonstate.edu](mailto:Gloria.Krahn@oregonstate.edu)

Sheryl A. Larson, PhD  
University of Minnesota  
[larso072@umn.edu](mailto:larso072@umn.edu)

Glenn Fujiura, PhD  
University of Illinois Chicago  
[gfujiura@uic.edu](mailto:gfujiura@uic.edu)

Tawara D. Goode, MA  
Georgetown University Medical Center  
[tdg2@georgetown.edu](mailto:tdg2@georgetown.edu)

Barbara L. Kornblau, JD  
Health Policy Advocacy Consulting  
Florida A&M University  
[barbarakornblau@gmail.com](mailto:barbarakornblau@gmail.com)

Citation: Havercamp, S.M., Krahn, G.L., Larson, S.A., Fujiura, G.T., Goode, T.D. & Kornblau, B.L. and the National Health Surveillance for IDD Workgroup (2019). *Identifying People with Intellectual Disability and Developmental Disabilities in National Surveys*. Intellectual and Developmental Disabilities.

*Acknowledgements*

We are grateful to members of the National Health Surveillance for IDD Workgroup: Jennifer Johnson, Andrew Morris, Amanda Reichard, Julie D. Weeks, Alissa Stevens, Ellen Blackwell, John Drabeck, Melissa Harris, Natasha Hollis, Helen Lamont, Bill Martin, Jennifer Madans, Dianne Rucinski, Hassan Ragy, and Kristen Robinson.

Current national health surveillance systems in the U.S. offer little or no information about the prevalence and health status of adults with intellectual disabilities (ID) or developmental disabilities (DD). In fact, the best data on which to base prevalence estimates for adults and children with intellectual and developmental disabilities (IDD) are based on a survey that was fielded in 1994 and 1995 (Larson, Lakin, Anderson, Kwak Lee, Lee, & Anderson, 2001). Health surveillance data are needed to allow population health researchers to track the incidence and prevalence of disability and health conditions, identify health disparities, and identify factors that influence or contribute to improved health (Fox, Bonardi, & Krahn, 2015). Federal and state agencies need accurate and timely data to make projections, establish policies, and plan and implement programs to serve people with IDD (see Krahn, this volume). Although people with IDD were estimated to account for less than 2% of the U.S. population (Larson, et al., 2001), as recipients of significant public and private expenditures, they are a policy relevant population. Long-term supports and services (LTSS), including institutional and home and community-based services (HCBS), accounted for 30% of all Medicaid expenditures in 2016, with 28% of all Medicaid-funded LTSS going to people with IDD (Eiken, Sredl, Burwell, & Amos, 2018). People with IDD also comprise 14% of all working-age Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) beneficiaries (Livermore, Bardos, & Katz, 2017). Public health and policy planning for adults with IDD is imperiled by the lack of ongoing national surveillance data on prevalence and health status. This paper reviews definitions of ID and DD, availability of prevalence and health surveillance data for adults with IDD and recommendations to address gaps in national surveillance activities for this population. We identify content gaps, methodological considerations, and design issues for identifying adults with IDD in survey research.

## **Disability Terms and Definitions**

Definitions of disability and the criteria used to meet disability determination vary widely across federal agencies (see Havercamp and Krahn, this volume). For this paper, DD is defined based on criteria specified in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) and ID is defined using the American Association on Intellectual and Developmental Disabilities' (AAIDD) definition (Schalock et al., 2010).

### **Developmental Disabilities**

The DD Act of 2000 (42 U.S.C. §15001 et seq.) defines DD as “a severe, chronic disability that is attributable to a mental or physical impairment, is manifested before the individual attains age 22, is likely to continue indefinitely, results in substantial functional limitations in three or more of the following areas of major life activity: self-care; communication; learning; mobility; self-direction; independent living; and economic self-sufficiency; and reflects the individual’s need for a combination and sequence of services and supports. Children from birth through the age of 9 years old with significant developmental delays and specific congenital or acquired conditions do not need to meet the functional limitations criteria to be considered to have DD.”

### **Intellectual Disability**

While ID is not defined in federal statute, the U.S. Supreme Court and federal entities such as the Administration on Community Living (ACL) and the President’s Committee for People with Intellectual Disability recognize the AAIDD definition, which states that ID is “a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which originates before the age of 18” (Schalock et al., 2010).

Intellectual functioning, or intelligence, refers to general mental ability including reasoning, planning, problem solving, thinking abstractly, comprehending complex ideas, learning quickly, and learning from experience. Significant limitation in intellectual functioning is operationally defined as an IQ score that is approximately two standard deviations below the mean (Schalock et al., 2010). Adaptive behavior is the collection of conceptual, social, and practical skills that have been learned and are performed by people in their everyday lives (Schalock et al., 2010). Conceptual skills include language, reading and writing, and time and number concepts. Social skills refer to interpersonal skills such as social responsibility, self-esteem, gullibility, following rules/obeying laws, and social problem solving. Practical skills include activities of daily living, occupational skills, use of money, safety, health care, travel/transportation, schedules/routines, and use of the telephone. For the diagnosis of ID, significant limitations in adaptive behavior are operationally defined as performance approximately two standard deviations below the mean of either (a) one of the three types of adaptive behavior (conceptual, social, or practical), or (b) an overall score on a standardized measure of conceptual, social, and practical skills.

### **Comparing intellectual disability with developmental disability**

While the definitions ID and DD overlap, there are important differences between them that must be considered when creating operational definitions to identify people with IDD in national health surveys. Not all people with DD, as defined by the DD Act, have limitations in intellectual functioning (e.g., some people with cerebral palsy or epilepsy), and not all people with ID report substantial functional limitations in three or more of the DD Act areas. Among adult sample members with IDD in the National Health Interview Survey Disability Supplement

(NHIS-D), 40% had both ID and DD, 26% had ID but not DD, and 34% had DD but not ID (Larson et al., 2001).

### **Health Surveillance Activities**

In preparing to review their funding formulas for states, AIDD sought current prevalence rates on IDD and found that IDD prevalence was based on NHIS-D data fielded in 1994 and 1995. In 2018, AIDD formed a workgroup comprised of representatives from key federal agencies and other national experts in health surveillance, IDD research, and disability policy to function as an expert consensus panel. Building upon previous research (Krahn & Fox, 2014; Krahn, Fox, Campbell, Ramon, & Jesien, 2010), the workgroup evaluated the availability of prevalence estimates and health surveillance data for people with IDD in the U.S. in the interest of updating prevalence estimates for both children and adults. The AIDD National Health Surveillance Workgroup identified several surveillance systems reporting prevalence estimates for children with IDD (See Anderson, Larson, MapleLentz & Hall-Lande, this volume) but was unable to identify a current nationally representative surveillance program through which prevalence estimates for ID and DD in adults could be updated. The workgroup was charged with identifying gaps in national health surveillance surveys to identify adult sample members with ID or DD and then prioritizing up to three critical missing data elements. In part because the National Health Interview Survey (NHIS: Centers for Disease Control & Prevention, 1997) collects data via face-to-face interviews, it is often regarded the “gold standard” for health surveillance. In collaboration with staff of the Center for Disease Control and Prevention’s National Center for Health Statistics (NCHS), the workgroup reviewed recent and current national surveys to identify content gaps and to recommend items that could be added to NHIS to identify IDD. This article describes key workgroup findings and recommendations.

## **National Public Health Surveillance Surveys**

Efforts to establish a unified framework for disability statistics pushed international and federal data collection programs to identify two sets of questions to identify people with disabilities in health surveillance and population research (see Table 1). The US Department of Health and Human Services (HHS) Data Standards identified six questions about functional limitations in seeing, hearing, mobility, cognition, self-care and independent living using a yes/no response (United States Census Bureau, n.d.). The HHS questions are now embedded into several population-based surveys including the American Community Survey (ACS), the Current Population Survey (CPS; US Census Bureau and U.S. Bureau of Labor Statistics, 2018), and the Survey of Income and Program Participation (SIPP; US Census Bureau, 2013). The Washington Group Short Set (WG-SS; The Washington Group on Disability Statistics, 2002) questions ask about difficulty with seeing, hearing, mobility, cognition, self-care and communication, but using a severity scale rather than a yes/no response option (Madans, Loeb, & Altman, 2011). The WG-SS items are included in the NHIS surveys and in international disability research.

-Insert Table 1-

While the use of a common set of disability identifiers on national surveys improves the consistency across surveys and prevalence estimates for disabilities in general, neither question set include enough specific items to identify people with IDD. For example, the ACS asks about “serious difficulty concentrating, remembering, or making decisions,” while the analogous WG-SS question asks about “difficulty concentrating or remembering.” These limitations may be attributable to many different conditions including neurocognitive disorders such as Alzheimer’s disease and stroke, neurodevelopmental disabilities such as ID and autism spectrum disorder

(ASD), mental health conditions such as schizophrenia and depression, and health conditions requiring medications that affect cognition.

To monitor the health status and outcomes of people with specific conditions, public health surveys ask respondents to name the condition causing reported limitations, or ask directly if the person has a condition. For example, the 2012 through 2018 NHIS and the 2008 through 2013 Survey of Income and Program Participation (SIPP, 2014) adult surveys asked whether respondents had ID. The SIPP also asked about related conditions including autism and cerebral palsy. The current National Survey of Children’s Health (NSCH) and the NHIS child questionnaire ask if a child has ID, ASD or “any other developmental delay diagnosis.” Prevalence estimates for ID, ASD, and developmental delay in children are updated regularly using NHIS and NSCH (e.g., Zablotsky, Black & Blumberg, 2017). Unfortunately, the SIPP and the NHIS have been redesigned and neither now asks adults if they have ID or other related conditions (see [https://www.cdc.gov/nchs/nhis/2019\\_quest\\_redesign.htm](https://www.cdc.gov/nchs/nhis/2019_quest_redesign.htm)).

### **Administrative Data Sets**

Several administrative data sets yield surveillance data for adults with IDD (see Bonardi, Krahn, Fay, Lulinski, this volume). For example, an AIDD funded Project of National Significance, the State of the States in Intellectual and Developmental Disabilities (Braddock, Hemp, Tanis, Wu, & Haffer, 2017), provides biennial updates on the determinants of public spending and programmatic trends for IDD services in the 50 states, the District of Columbia, and the United States as a whole. Administrative claims and eligibility data from the Centers for Medicare & Medicaid Services (CMS) and the Social Security Administration include identifiers for ID and related conditions. Surveys of service recipients such as the Medicare Current

Beneficiary Survey (MCBS; see Haile, Reichard, and Morris, this volume), the Medicaid HCBS Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey, Social Security's National Beneficiary Survey (NBS), and the National Core Indicators (NCI) provide individual level data about the characteristics and experiences of random samples of service recipients.

Although administrative datasets offer information about program recipients, those data are not generalizable to the general population because they exclude non-recipients whose characteristics may be dissimilar to those of recipients. Furthermore, while some administrative data sets include people in all states, the District of Columbia, and Puerto Rico, many do not include people in other U.S. territories (Guam, American Samoa, U.S. Virgin Islands, and Northern Mariana Islands). Combined data from Medicare and Medicaid claims capture a larger portion of the IDD population, but variability in identification rates across states limit generalizability (see CMS, March 2015).

### **Strategies for Identifying People with IDD in National Surveys**

The workgroup first identified essential domains in the definitions of ID and DD, reviewed items from past versions of the NHIS, SIPP and World Health Organization Disability Assessment Scale (WHO-DAS) covering those domains, then nominated items that could be added to the NHIS 2018-R to identify adult sample members with ID or DD. The nominated items were prioritized to identify the top three. Finally, the workgroup reviewed methodological considerations for identifying respondents with IDD in survey research, with particular attention to cultural diversity related to race and ethnicity.

### **Essential Domains**

Table 2 lists essential domains in the AAIDD definition of ID and the DD Act definition of DD and shows the overlap between these definitions. Discrete skills are indented within



conceptual categories. Check marks indicate domains mentioned in the definitions of ID or DD and the final column indicates whether or not the NHIS 2018-R adult survey contains one or more questions in each domain. The DD Act definition requires that the person have substantial functional limitation in three or more of the major life domains, while the AAIDD definition requires that the person score two or more standard deviations below average in intellectual functioning and in at least one adaptive behavior domain.

-Insert Table 2-

*Intellectual Functioning.* Intellectual functioning is general mental ability (Schalock et al., 2010). It includes reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas, learning quickly, and learning from experience. The ID definition describes conceptual skills as including language, reading and writing, money, time, and number concepts (Schalock et al., 2010). Limitations in intellectual functioning are required for a diagnosis of ID. In surveys such as the NHIS, SIPP and NSCH, people with ID are often identified through questions asking if the respondent has a diagnosis of ID or if ID caused a reported limitation. In the DD Act, the emphasis is on whether the person experiences a significant limitation in lifelong learning. Functional limitations in learning and conceptual skills can be assessed on surveys using questions such as “*Does \_\_\_\_\_ have serious difficulty learning how to do things most people their age can learn?*” from the NHIS-D, and “*In the last 30 days how much difficulty did you have in analyzing and finding solutions to problems in day to day life*” or “*In the last 30 days how much difficulty did you have learning a new task, for example, learning how to get to a new place*” from the World Health Organization’s Disability Assessment Schedule 2.0 (WHO-DAS; Ustun et al, 2010).

*Communication.* Communication is a major life activity in the DD Act definition of DD and language is a skill within the social skills domain of adaptive behavior in the AAIDD definition of ID. The NHIS 2018-R item is “*Using your usual language, do you have difficulty communicating, for example, understanding or being understood?*” Items from the WHODAS 2.0 (2010) include “*In the last 30 days, how much difficulty did you have in generally understanding what people say?*” and “*In the past 30 days, how much difficulty have you had starting and maintaining a conversation?*”

*Social skills.* Social skills are a domain of adaptive behavior in the definition of ID, but are not specifically covered in the DD Act definition. Social skills include interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized (Schalock et al., 2010). The NHIS 2018-R asks “*Because of a physical, mental or emotional condition do you have difficulty participating in social activities such as visiting friends, attending clubs and meetings, or going to parties?*” The WHO-DAS 2.0 includes five items on social skills asking, “*How much of a problem do you have dealing with people you do not know; maintaining a friendship; getting along with people who are close to you; making new friends; and joining in community activities?*”

*Self-care.* Limitations in self-care, such as difficulty dressing, grooming, and eating, are essential activities of daily living identified in the DD Act of 2000 and of adaptive behavior as defined in the AAIDD definition of ID (Shalock, 2010). The NHIS 2018-R asks, “*Do you have difficulty with self-care, such as washing all over or dressing?*” (NHIS 2016).

*Independent living skills.* Independent living skills include use of money, safety, health care, transportation, housework, and preparing meals. The ACS asks, “*Because of a physical,*

*mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?"* The NHIS 2018-R adds this follow up question, "*Would you say no difficulty, some difficulty, a lot of difficulty, or are you unable to do this?"*

*Self-direction.* Self-direction refers to the *ability* to make choices about one's life. Self-direction was named as one of the seven domains in the DD Act definition but was not mentioned or defined elsewhere in the Act, and was not included in the AAIDD definition of ID. While the terms self-direction and self-determination are often used interchangeably, self-determination emphasizes *opportunity* to make choices about one's life and is measured in terms of activities and environmental supports that offer opportunities to communicate choices and exercise control over one's life (e.g., Abery, Smith, Springborg & Stancliffe, 2007). In the DD Act, self-determination was mentioned twelve times as a principle or goal of services. For example, *It is the policy of the United States that ... this title shall be carried out in a manner consistent with the principles that- 1) individuals with developmental disabilities... are capable of self-determination, independence, productivity, and integration and inclusion in all facets of community life* (DD Act 101c).

Several different definitions of self-direction have been proposed. CMS offers a self-direction option to some Medicaid HCBS recipients allowing them or their representatives to have decision-making authority over certain services and responsibility to manage them with the assistance of a system of available supports (CMS, n.d.). Researchers defined self-direction for the purpose of identifying adults with DD in the NHIS-D as 1) "*needing to be reminded or have someone close by*" for dressing, eating, bathing, toileting or transferring because of a physical, mental or emotional problem; 2) having or needing "*a case manager to coordinate personal care, social or medical services*"; or 3) having "*a court appointed guardian*" in the previous 12

months (Larson et al., 2001). However, rather than adopting any of these approaches, the workgroup noted that additional time and development work was needed to develop one or more items to assess functional limitations in self-direction.

*Economic self-sufficiency.* The DD Act identifies economic self-sufficiency as a major life activity. Occupational skills are included among the practical skills for a diagnosis of ID. For people with IDD, being unable to work or being limited in the amount or kind of work one is capable of are not the only reasons people are unemployed. Other factors include limited or no access to appropriate employment supports and transportation (Winsor, Timmons, Butterworth, Migliore, Domin, Zalewska & Shepard, 2018). While some surveys ask about employment supports, doing so would require additional survey questions. Adults with DD were identified in the NHIS-D if the person 1) “*has never been able to work*” or is “*currently unable to work because of a mental or emotional problem;*” 2) “*is limited in kind or amount of work;*” 3) “*has trouble finding or keeping a job or doing job tasks because of mental/emotional problems;*” or 4) has “*participated in*” or is “*on the waiting list for*” a sheltered workshop, transitional work training, supported employment or a day activity center (Larson et al., 2001).

*Mobility.* Mobility was identified as a major life activity in the DD Act of 2000 but is not part of the definition of ID (Schalock et al., 2010). The NHIS 2018-R asks 24 questions about mobility limitations one of which is “*Do you have difficulty walking or climbing steps?*”

*Severity.* Impairment severity is an important qualifier to distinguish IDD from conditions less consequential or pervasive. Developmental disabilities are defined as *severe and chronic* conditions that result in *substantial functional limitations* in three or more areas of major life activity. Similarly, ID is characterized by *significant limitations* in intellectual functioning and adaptive behavior (Schalock et al., 2010). Therefore, for survey items to be useful in identifying

people with ID or DD, an indicator of the severity is needed. The NHIS 2018-R offers response options of “*no difficulty, some difficulty, a lot of difficulty, cannot do at all*” for its questions on functional limitations and is therefore well suited for this purpose. Only people who report “*a lot of difficulty*” or “*cannot do at all*” would be considered to have a substantial functional limitation.

*Age of onset.* Both intellectual and developmental disabilities are conceptualized as lifelong conditions that are first apparent during the developmental period. This onset criteria is operationalized in the AAIDD definition of ID as before the age of 18, and in the DD Act definition of DD as before the age of 22. Survey items measuring the age of onset are important to distinguish IDD from neurocognitive disorders and other conditions related to an illness or injury in adulthood. The NHIS-D asked about the age at onset for each functional limitation but the NHIS 2018-R does not. The workgroup determined that, given the task of identifying no more than three questions, it would not be feasible to ask about age of onset for every functional limitation item. Rather, when a substantial limitation in any of the qualifying limitations is endorsed, a single follow up question asking if any of those limitations first occurred before the person was [18 or 22] years old would be a reasonable alternative.

*Expected duration.* Both ID and DD are conceptualized as *lifelong conditions*, first apparent during the developmental period, the impact of which can be reduced through the application of supports. While the AAIDD definition did not specify duration as a criterion for diagnosis of ID, the DD Act specifies that the condition is likely to continue indefinitely and require ongoing services and supports. The NHIS-D asked about the expected duration of each functional limitation with “more than 12 months” being the longest available response. The workgroup determined that, given the task of identifying no more than three questions, it would

not be feasible to ask about expected duration for every functional limitation item and that the expected duration construct may be difficult to reliably assess in a national survey.

### **Content Gaps, Methodological Considerations, and Design Issues**

After reviewing the status of the surveillance system, workgroup members moved on to identify and prioritize content gaps, methodological considerations and design issues for improving the system.

#### **Content gaps**

To update prevalence estimates for IDD, as defined in the DD Act of 2000 and AAIDD, would require survey items covering each of the domains specified in the Act as well as items to assess age at onset, severity, and lifelong duration. As shown in Table 2, The NHIS 2018-R included at least one item in the DD Act domains of self-care, communication, mobility and economic self-sufficiency. However, the NHIS 2018-R lacked items on intellectual functioning, social skills, independent living skills, self-direction, age of onset, and expected duration of disability. Interestingly, the NHIS 2018-R includes an item on social participation, which, while not currently included in the definitions of ID or DD, plays an important role in health and function (Scott & Havercamp, 2018a; World Health Organization, 2001).

#### **Methodological considerations**

Because of the nature of IDD, special care must be taken in designing survey items and methods. These methodological considerations include the choice of assessing function versus diagnoses, single versus multiple item sets, and self versus proxy reporting.

*Function vs. Diagnosis.* Items designed to identify people with IDD vary greatly, and may use either diagnostic conditions, functional limitations, or both. Many health care services, medical care reimbursement, and rehabilitation studies are based on diagnostic conditions. The Social Security Administration relies on detailed medical diagnoses as its first step in determining eligibility for its entitlement programs followed by determination of one's ability to work (Livermore, Bardos, & Katz, 2017). Alternatively, the Maternal and Child Health Bureau (MCHB) made a distinct change in its basis for service eligibility from diagnostic categories to a more functional model to identify "children with special health care needs" (HRSA, n.d.). Data from the Department of Education's special education services reflects a combination of diagnostic categories and severity of functional impairment (National Center for Education Statistics, n.d.).

The umbrella concepts of substantial impairments in intellectual functioning, adaptive behavior, and major life activities emphasize a multidimensional view of IDD. However, the construction of survey questions to identify people with IDD largely reflects a narrower view of disability that emphasize either the diagnostic condition or the consequences of a condition. This approach is usually operationalized as questions about the presence of a condition ("*Does \_\_\_\_ have an intellectual disability?*") or limitations in specific functions, life activities, or need for supports ("*Does \_\_\_\_ have difficulty learning or engaging in activities typical for their age?*"). To order to identify people with IDD, questions about limitations in function or activities are sometimes enhanced by subsequent questions about causation (e.g., "*What condition is the cause of the limitation?*").

*Single Questions vs. Multiple Question-Sets.* Of the few recurring population-based or administrative data systems that screen for IDD, most use a single condition-based item to

classify participants (Bonardi et al, 2011). Notable exceptions were the NHIS-D and the SIPP prior to its most recent redesign. Capturing a multidimensional view of IDD typically requires more than a single question indicating inclusion or exclusion from a diagnostic group.

Hendershot et al. (2005) found that IDD identification using a condition-based screen (“*Do you have intellectual disability?*”) versus a cause of limitation question (“*Is intellectual disability the primary cause of the limitation?*”) resulted in overlapping but not totally congruent samples.

The reliability and validity of survey-based IDD identification improves as the number of questions increases. The optimal number of questions to identify IDD, and their content and wording are yet to be determined, but it is clear that more questions will provide more precision and multidimensionality.

*Self vs. Proxy Reporting.* One of the unique challenges in developing and testing survey items that specifically target people with IDD is that people in this population are significantly more likely to require assistance from a proxy respondent to respond to some or all of the survey questions. Proxy responses are allowed on the NHIS; in the 2001-2002 NHIS Adult Survey, proxy responses were used for 59.3% of adults with IDD versus 1.2% of all adults (Hendershot, 2004). Research examining concordance between self-report and proxy-report has highlighted that (a) knowledge of the person by the proxy and (b) the nature of the construct measured are important in determining degree of agreement (e.g., Schmidt et al, 2010; Claes et al, 2012). Specifically, responses from close family members align more closely with self-report than do proxy-responses of acquaintances such as paid support staff and questions related to internal experiences are at greater risk of discordance than objective, externally verifiable questions (Scott & Havercamp, 2018b, Scott & Havercamp, 2018c). Finally, whether by self- or proxy-



report, stigma and related reluctance to disclose limitations in intellectual and developmental functioning are suspected to contribute to potential under-reporting.

### **Representing the Diversity of the United States in Health Surveillance**

In order for population health surveys to inform policy and programmatic decisions about IDD, items identifying adults with IDD must be included. Methodological decisions must be carefully considered to ensure the sampling frame captures a representative sample, and to ensure that planned analyses explore health disparities among vulnerable groups.

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). This Act has implications for the importance of 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 a survey, surveillance is incomplete and the unique interests and needs of excluded groups can neither be identified nor met. Including racially, ethnically, and linguistically diverse populations in surveys requires that the survey design incorporate a sampling frame that contains these populations and, ideally, oversamples for underrepresented groups. It also requires that the construction of the items and instructions for questionnaires are appropriate for the diverse populations who reside in the U.S., territories, and tribal communities (Statistical and Science Policy Office, 2016). Lastly, survey design must address linguistic competence by including individuals with limited English proficiency, those who have low literacy skills or are not literate, individuals with disabilities, and those who are deaf or hard of hearing. Linguistic competence requires the capacity to respond effectively to the health and

mental health literacy needs of populations. (Goode, Jones, Christopher & Brown, 2017; USHHS, 2014).

The *HHS Action Plan to Reduce Racial and Ethnic Health Disparities* (U.S. Department of Health and Human Services Office of Minority Health, 2011). This plan provides guidance for reducing disparities in health and health care. 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). In their scoping review of IDD prevalence, Anderson et al (this volume) identified no studies reporting differences by race, ethnicity, or linguistic group amongst adults with IDD. As Goode et al. (2014) noted, health disparities research within racial, ethnic, and disability groups has 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 Department of Health and Human Services Office of Minority Health, 2014) outline standards and specify practices that are appropriate for questionnaire design that maximizes the comparability of survey questions across cultures and reduces measurement error.

*Data Collection in the Territories.* Understanding prevalence of IDD at a national level 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, ACS, and SIPP, the omission of the other U.S. territories from NHIS and most population-based surveys limits the ability to estimate prevalence and understand health outcomes of all Americans with IDD.

### **Workgroup Recommendations**

AIDD National Health Surveillance Workgroup described the essential domains to identify adults as having ID or DD in national surveys. They were then asked to construct a minimal question set (i.e., three items or fewer) that could be used to identify IDD for NHIS and other surveys. The workgroup prioritized domains that 1) were common to both ID and DD definitions, 2) were absent from the NHIS 2018-R, and 3) had items measuring the domain that had previously been used in national surveys. The workgroup recommended the following three domains to augment the NHIS: 1) intellectual functioning, 2) independent living, and 3) age of onset. With the addition of these domains, the only essential domains not captured by the NHIS are self-direction and expected duration of limitation, which were considered difficult to measure reliably, and social skills, which is not currently part of the DD Act definition.

### **Conclusions and Next Steps**

Changes to national health surveillance systems provide a challenge and an opportunity. This national surveillance workgroup concluded with four top priority areas and steps to improve health surveillance of adults with IDD.

1. The most recent survey supporting prevalence estimates for ID or DD in adults was fielded in 1995. Twenty-four years is far too long to wait for updated prevalence estimates for this growing segment of the population. While several ongoing surveillance programs provide updated prevalence estimates for IDD in children, prevalence estimates

vary by age. Ongoing assessment of prevalence rates for adults is critical so that assumptions made about life trajectories of people with IDD can be informed by research. Periodic reviews of the instruments and survey items used to monitor prevalence rates are needed to ensure that they remain relevant as the US population changes.

2. The AAIDD/ACL and its partners are now collaborating with research staff at the NCHS Collaborative Center for Questionnaire Design and Evaluation Research at the CDC to construct and cognitively test survey questions that are valid, reliable, and appropriate to identify adults with IDD in national surveillance surveys. Items to identify adults with IDD are tentatively scheduled to be added to the 2021 NHIS. While our recommendations focus on updates to the NHIS survey, the analyses and conclusions of the workgroup could also be applied to other national surveillance surveys as those surveys undergo review and revision.
3. The US population is increasingly culturally diverse. To account for the increasing diversity, intentional efforts are needed to explore health patterns across race and ethnicity in combination with disability to allow us to understand and improve population health. Residents of US territories must be included in the sampling frame of national surveillance systems. This also requires researchers who use national surveillance system data to disaggregate and report race, ethnicity and the interaction between race, ethnicity and disability in health outcomes.
4. This project was marked by a notably high level of cooperation across federal agencies and with the broader disability community. The workgroup strongly supports continued use of this model for collaboration in future health surveillance activities.

With commitment and collaboration across federal, state, public, and private partners, adults with IDD will become visible in health surveillance data so that publicly funded services and supports can better meet their health needs.

*It always seems impossible until it is done.*

*-Nelson Mandela*

## References

- Abery, B. H., Smith, J. (Ed.), Elkin, S. (Ed.), Springborg, H. (Ed.), & Stancliffe, R. (Ed.) (2007). *The Minnesota Self-Determination Scales-Revised: Environment Scale*. Minneapolis, MN: University of Minnesota, Institute on Community Integration.
- American Community Survey (ACS)*. (2017). Washington, DC: U.S. Census Bureau. Available at <https://www.census.gov/programs-surveys/acs/>
- Bonardi, A., Lauer, E., Mitra, M., Bershady, J., Taub, S., Noblett, C. (2011). Expanding surveillance of adults with intellectual disability in the US. Center for Developmental Disabilities Evaluation and Research (CDDER). E.K Shriver Center, University of Massachusetts Medical School. Retrieved from: <http://www.umassmed.edu/Content.aspx?id=157548&linkidentifier=id&itemid=157548>
- Braddock, D., Hemp, R., Tanis, E., Wu, J., Haffer, L. (2017). *The state of the states in developmental disabilities* (11<sup>th</sup> Edition). Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Centers for Medicare and Medicaid Services (n.d.). Retrieved from: <http://www.cms.gov>
- Centers for Medicaid and Medicare (March, 2015). Balancing Incentive Program: Summary of States' Core Standardized Assessment Instruments. Retrieved from: <https://www.medicaid.gov/medicaid/ltss/downloads/balancing/data-collection-state-summary.pdf>
- Civil Rights Act of 1964, U.S. Public Law 88-352, 241 *et seq.*
- Claes, C., Vandeveld, S., Van Hove, G., van Loon, J., Verschelden, G., & Schalock, R. (2012). Relationship between self-report and proxy ratings on assessed personal quality of life-

related outcomes. *Journal of Policy and Practice in Intellectual Disabilities*, 9(3), 159-165.

US Census Bureau and U.S. Bureau of Labor Statistics (2018). Current Population Survey (CPS). Washington, DC: U.S. Census Bureau and. Retrieved from <https://www.census.gov/programs-surveys/cps/technical-documentation/questionnaires.html>

Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 U.S.C.A. 15001

Eiken, S., Sredl, K., Burwell, B., & Amos, A. (2018). *Medicaid expenditures for long-term services and supports for FY 2016*. Washington, DC: IBM Watson Health. Available for download at <https://www.medicare.gov/medicaid/ltss/reports-and-evaluations/index.html>.

Fox, M.H., Bonardi, A., & Krahn, G.L. (2015). Expanding public health surveillance for people with intellectual and developmental disabilities in the United States. *International Review of Research in Developmental Disabilities*, 48(4), 73–114.

Goode, T. D., Carter-Pokras, O. D., Horner-Johnson, W., & Yee, S. (2014). Parallel tracks: Reflections on the need for collaborative health disparities research on race/ethnicity and disability. *Medical Care*, 52(10), S3.

Goode, T., Jones, W., Christopher, J. Brown, I., Responding to cultural and linguistic differences among people with intellectual disability (2017). In M. Percy, M.L. Wehmeyer, K.A. Shogren, & A. Fung (Eds.) *A comprehensive guide to intellectual and developmental disabilities* (2nd ed.). Baltimore: Brookes Publishing. (pp 389-400).

Hendershot, J. (2004). Response patterns among adult respondents with mental retardation in the National Health Interview Survey, 1997-2002. *DD Data Brief*, 6(2). Minneapolis: University of Minnesota, Research and Training Center on Community Living.

Hendershot, G., Larson, S., Lakin, C., & Doljanac R. (2005). *Problems in defining mental retardation and developmental disability: Using the National Health Interview Survey. DD Data Brief, 7(2)*. Minneapolis: University of Minnesota, Research and Training Center on Community Living. Available at: <https://rtc.umn.edu/docs/dddb7-1.pdf> [Accessed November 17, 2018].

*HHS action plan to reduce racial and ethnic health disparities: A nation free of disparities in health and health care* (2011). Washington, DC: U.S. Department of Health and Human Services. Retrieved from [https://minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS\\_Plan\\_complete.pdf](https://minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS_Plan_complete.pdf)

Horner-Johnson, J., & Dobbertin, K. (2014). Usual source of care and unmet health care needs: Interaction of disability with race and ethnicity. *Medical Care, 52*, 40-50.

HRSA, Maternal and Child Health. (n.d.). MCH Timeline: Omnibus Budget Reconciliation Act of 1981. Available at: <https://mchb.hrsa.gov/about/timeline/index.asp>. Accessed 6.28.2018.

Krahn, G. L., & Fox, M. H. (2014). Health disparities of adults with intellectual disabilities: what do we know? What do we do?. *Journal of Applied Research in Intellectual Disabilities, 27(5)*, 431-446.

Krahn, G., Fox, M. H., Campbell, V. A., Ramon, I., & Jesien, G. (2010). Developing a health surveillance system for people with intellectual disabilities in the United States. *Journal of Policy and Practice in Intellectual Disabilities, 7(3)*, 155-166.

Larson, S. A., Lakin, K. C., Anderson, L., Kwak Lee, N., Lee, J. H., & Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the



- 1994/1995 National Health Interview Survey Disability Supplements. *American Journal on Mental Retardation*, 106(3), 231-252.
- Livermore, G.A., Bardos, M., & Katz, K. (2017). Perspectives: Supplemental Security Income and Social Security Disability Insurance beneficiaries with intellectual disability. *Social Security Bulletin*, 77, 17.
- Madans, J. H., Loeb, M. E., & Altman, B. M. (2011). Measuring disability and monitoring the UN Convention on the Rights of Persons with Disabilities: The work of the Washington Group on Disability Statistics, *BMC Public Health*,11(4), S4.
- National Center for Education Statistics. Fast Facts. Available at <https://nces.ed.gov/fastfacts/display.asp?id=64>. Accessed 6.28.2018.
- National Health Interview Survey (NHIS)*. (1997). Washington, DC: Centers for Disease Control & Prevention, National Center for Health Statistics. Available at [https://www.cdc.gov/nchs/nhis/nhis\\_questionnaires.htm](https://www.cdc.gov/nchs/nhis/nhis_questionnaires.htm)
- National Health Interview Survey - Child (NHIS-Child)*. (2012). Washington, DC: Centers for Disease Control & Prevention, National Center for Health Statistics. Available at [http://action.cahmi.org/learn/NHIS-Child/topics\\_questions](http://action.cahmi.org/learn/NHIS-Child/topics_questions)
- National Health Interview Survey on Disability (NHIS-D)*. (1994-1995). Washington, DC: Centers for Disease Control & Prevention, National Center for Health Statistics. Available at [https://www.cdc.gov/nchs/nhis/nhis\\_disability.htm](https://www.cdc.gov/nchs/nhis/nhis_disability.htm).
- National standards for culturally and linguistically appropriate services in health and health care*. (n.d.) Washington, DC: U.S. Department of Health and Human Services. Retrieved from <https://www.thinkculturalhealth.hhs.gov/clas/standards>

- National Survey of Children's Health (NSCH)*. (2018). Washington, DC: U.S. Department of Health and Human Services, Health Resources Administration, Maternal and Child Health Bureau. Available at <https://mchb.hrsa.gov/data/national-surveys/questionnaires-datasets-supporting-documents>
- Onyeabor, S. (2016). Addressing health disparities at the intersection of disability, race, and ethnicity: The need for culturally and linguistically appropriate training for healthcare professionals. *Journal of Racial and Ethnic Health Disparities*, 3(3), 389-393.
- Peterson-Besse, J.J., Walsh, E.S., Horner-Johnson, W., Goode, T.D., Wheeler, B. (2014). Barriers to health care among people with disabilities who are members of underserved racial/ethnic groups: A scoping review of the literature. *Medical Care*, 52, 51-63.
- Education for all Handicapped Children Act of 1975, U.S. Public Law 94-142. U.S.C. 20, sec 1401 *et seq.*
- Schalock, R. L., Borthwick-Duffy, S.A., Bradley, V. J., Buntinx, W. H., Coulter, D. L., Craig, E. M., Gomez, S.C... Yeager, M.H. (2010). *Intellectual disability: Definition, classification, and systems of supports*. Washington DC: American Association on Intellectual and Developmental Disabilities.
- Schmidt, S., Power, M., Green, A., Lucas-Carrasco, R., Eser, E., Dragomirecka, E. & Fleck, M. (2010). Self and proxy rating of quality of life in adults with intellectual disabilities: Results from the DISQOL study. *Research in Developmental Disabilities*, 31(5), 1015-1026.
- Scott, H. M., & Haverkamp, S. M. (2018a). Promoting Wellness in People with Intellectual and Developmental Disabilities Through Relationships. *Current Developmental Disorders Reports*, 5(3), 150-156

Scott, H. M., & Havercamp, S. M. (2018b). Comparisons of self and proxy report on health-related factors in people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 31(5), 927-936.

Scott, H. M., & Havercamp, S. M. (2018c). Comparison of Self-and Proxy Report of Mental Health Symptoms in People With Intellectual Disabilities. *Journal of Mental Health Research in Intellectual Disabilities*, 11(2), 143-156.

Subcommittee on Questionnaire Evaluation Methods (2016). *Evaluating survey questions: An inventory of methods*. Statistical Policy Working Paper 47. Washington, DC: Statistical and Science Policy Office, Office of Information and Regulatory Affairs, US Office of Management and Budget. Downloaded May 22, 2019 from

<https://s3.amazonaws.com/sitesusa/wp-content/uploads/sites/242/2014/04/spwp47.pdf>

*Survey of Income and Program Participation (SIPP) Social Security Supplement*. (2013).

Washington, DC: U.S. Census Bureau. Available at <https://www.census.gov/programs-surveys/sipp/about/SSA-Supplement.html>

Survey Research Center. (2016). *Guidelines for best practice in cross-cultural surveys*. Ann Arbor, MI: Survey Research Center, Institute for Social Research, University of Michigan. Retrieved June 1, 2018, from <http://www.ccsr.isr.umich.edu/>

*The Washington Group Short Set (WG Short Set)*. (2002). Hyattsville, MD: The Washington Group on Disability Statistics. Available at <http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/The-Washington-Group-Short-Set-of-Questions-on-Disability.pdf>

- U.S. Census Bureau (2014). *Survey of Income and Program Participation (SIPP)*. Washington, DC: U.S. Census Bureau. Available at <https://www.census.gov/programs-surveys/sipp/tech-documentation/questionnaires.html>
- U.S. Department of Health and Human Services, Office of Minority Health. (2014, April). *National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care: A Blueprint for Advancing and Sustaining CLAS Policy and Practice*. Washington, DC: Author.
- Ustuen, T.B., Chatterji, S., Kostanjsek, N., Rehm, J., Kennedy, C., Eping-Jordan, J., Saxena, S., Von Korff, M., & Pull, C. (2010). WHO/NIH Joint Project. *Developing the World Health Organization Disability Assessment Schedule 2.0*. *Bulletin of the World Health Organization*, 88(11): 815-23.
- Winsor, J., Timmons, J., Butterworth, J., Migliore, A., Domin, D., Zalewska, A., & Shepard, J. (2018). *StateData: The national report on employment services and outcomes*. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0)*. (2010). Geneva: WHO Press. Available at <https://www.who.int/classifications/icf/whodasii/en/>
- World Health Organization (2001). *International Classification of Functioning, Disability and Health (ICF)*. Retrieved from <http://www.who.int/classifications/icf/en/>
- Yee, S., Breslin, M.L., Goode, T.D., Havercamp, S.M., Horner-Johnson, W., Iezzoni, L.I., & Krahn, G. (2018). *Compounded disparities: Health equity at the intersection of disability, race, and ethnicity*. Commissioned paper for the National Academies of Sciences, Engineering and Medicine. Retrieved from:

<http://nationalacademies.org/hmd/Activities/SelectPops/HealthDisparities/Commissioned-Papers/Compounded-Disparities.aspx>. [Accessed June 15, 2018]

Zablotsky, B., Black, L.I., Maenner, M.J., & Blumberg, S.J. (November 2017). *Estimated Prevalence of Children with Diagnosed Developmental Disabilities in the United States 2014-2016. National Center for Health Statistics Data Brief, No. 291*. Washington DC: U.S. Department of Health and Human Services. Retrieved from: <https://www.cdc.gov/nchs/data/databriefs/db291.pdf>

Table 1

*Disability Identifiers on National Surveys*

<b>Domain</b>	<b>Washington Group- Short Set</b>	<b>US Department of Health and Human Services Data Standards on Disability Status</b>
Vision	Do you have difficulty seeing, even if wearing glasses	Are you blind or do you have serious difficulty seeing, even when wearing glasses?
Hearing	Do you have difficulty hearing, even if using a hearing aid?	Are you deaf or do you have serious difficulty hearing?
Mobility	Do you have difficulty walking or climbing steps?	Do you have serious difficulty walking or climbing stairs? (5 years old or older)
Cognition	Do you have difficulty remembering or concentrating?	Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)
Self-care	Do you have difficulty (with self-care such as) washing all over or dressing?	Do you have difficulty dressing or bathing? (5 years old or older)
Communication	Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?	
Independent Living		Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (15 years old or older)



Table 2

*Crosswalk between domains essential to identify ID and DD and NHIS 2018-R content*

	<b>Intellectual Disability (AAIDD)</b>	<b>Developmental Disabilities (DD Act)</b>	<b>NHIS 2018-R Sample Adult Survey</b>
<b>Major life activity domain</b>			
Intellectual functioning	√		
Adaptive Behavior	√		
Conceptual skills	√	√	
Learning	√		
Self-direction			√
Practical skills	√		
Self-care	√	√	√
Independent living skills	√	√	√
Economic self-sufficiency	√	√	√
Social skills	√		
Communication	√	√	√
Mobility		√	√
<b>Other criteria</b>			
Age of onset	√ (Before age 18)	√ (Before age 22)	
Severity	√	√	√
Lifelong duration		√	