Working Through the Data Conundrum: Identifying People with Intellectual and Developmental Disabilities in National Population Surveys

Administration on Intellectual and Developmental Disabilities
Administration for Community Living

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Center for Clinical Standards and Quality, Centers for Medicare & Medicaid Services (CCSQ/CMS)

National Center for Health Statistics, Centers for Disease Control & Prevention (NCHS/CDC)

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Acknowledgements

I am pleased to present this report "Working through the Data Conundrum: Identifying People with Intellectual and Developmental Disabilities in National Population Surveys." This report results from a highly productive partnership of public agencies and private individuals to address the need for better health surveillance data on people with intellectual and developmental disabilities, a problem that has been recognized since the Surgeon General's 2001 report.

This report builds on previous work of HHS. Most notable is the work of the National Center on Birth Defects and Developmental Disabilities of the Centers for Disease Control and Prevention (CDC) with their early and ongoing focus to identify the health promotion needs of this population and that of the National Center for Health Statistics, CDC, which provides international leadership on improving health surveillance of all populations.

To ensure quality of life for individuals with intellectual and developmental disabilities, it is critical that we continue to advance discussions and efforts around health surveillance for this highly diverse population. We hope that this report and the work behind it will lead the nation forward in ensuring policies and programs are in place that support people with intellectual and developmental disabilities to live with respect and dignity as fully participating members of their communities.

I'm deeply thankful for the collaborations with the other HHS agencies who committed their effort and attention to this initiative. These include the CDC's NCHS and NCBDDD; ACL's NIDILRR and AIDD staff; HHS's ASPE; and CMS's CMCS, CCSQ and OMH. The work was facilitated and enriched by the contributions of researchers and disability organizations that contributed generously with their time under the leadership of Susan Havercamp and Gloria Krahn. Finally, I'd like to acknowledge the contributions of Andrew Morris of CPE, ACL, who provided the internal management and coordination that brought this report to completion.

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Contents

Acronyms

AAIDD	American Association on Intellectual and Developmental Disabilities
ACL	Administration for Community Living, HHS
ACS	American Community Survey
ADA	Americans with Disabilities Act
ADDM	Autism and Developmental Disabilities Monitoring
ADL	Activities of Daily Living
AIDD	Administration on Intellectual and Developmental Disabilities, ACL, HHS
AI/AN	American Indian/Alaska Native
ASD	Autism Spectrum Disorder
ASPE	Assistant Secretary for Planning and Evaluation, HHS
AUCD	Association of University Centers on Disabilities
CCQDER	Collaborating Center for Questionnaire Design and Evaluation Research
CDC	Centers for Disease Control & Prevention
CMS	Centers for Medicare & Medicaid Services
CERIIDD	Center for Epidemiological Research for Individuals with Intellectual and Developmental Disabilities
CP	Cerebral Palsy
CPS	Current Population Survey
DD	Developmental Disabilities
DD Act	Developmental Disabilities Assistance and Bill of Rights Act of 2000
HCBS	Home & Community Based Services
HHS	Health & Human Services, U.S. Department of
HRSA	Health Resources and Services Administration
HSRI	Human Services Research Institute
IADL	Instrumental Activities of Daily Living
ICDR	Interagency Committee on Disability Research
ID	Intellectual Disability
IDD	Intellectual and Developmental Disabilities
LTSS	Long-term Supports and Services
MCHB	Maternal and Child Health Bureau, HRSA, HHS
MR	Mental Retardation [term has been replaced by Intellectual Disability]
NACDD	National Association of Councils on Developmental Disabilities
NASDDDS	National Association of State Directors of Developmental Disabilities Services
NCHS	National Center for Health Statistics, CDC
NCI	National Core Indicators
NHIS	National Health Interview Survey
NHIS-D	National Health Interview Survey - Disability Survey (1994-1995)
NSCH	National Survey of Children's Health
OMH	Office of Minority Health, CMS
OMH	Office of Minority Health, HHS
SB	Spina Bifida
SIPP	Survey of Income and Program Participation

Executive Summary

Surveillance data allow policy analysts and population health researchers to track the size and nature of target populations, to identify health disparities, and to determine characteristics that contribute to health. However, for the population of people with intellectual and developmental disabilities (IDD), there is no national effort to collect such surveillance information.

In an effort to better understand the health status and prevalence of people with IDD in the U.S., a workgroup comprised of key agencies within the U.S. Department of Health and Human Services (HHS) and other experts in the field of IDD convened during the first half of 2018 to review the current landscape and future directions related to surveillance for people with IDD. This paper describes the need for, availability of, and recommendations for changes in surveillance data about people with IDD, particularly adults. Priority criteria for identifying people with IDD relate to measurements of learning, independent living, and age of onset. Additional identifying criteria relate to measurements of communication, self-direction, and expected duration. This is one of two companion workgroup reports; the other report is *Enriching our Knowledge: State and Local Data to Inform Health Surveillance of the Population with Intellectual and Developmental Disabilities* (2019).

The Data Conundrum

Currently, there is no systemic national research effort addressing the prevalence and health status of adults with IDD. People with disabilities broadly defined are identifiable in a number of national surveys that include the American Community Survey (ACS, the Current Population Survey (CPS), and the Survey of Income and Program Participation (SIPP) using six standard disability items. However, the identification questions are too broad to be useful in identifying people with IDD as based on statutory definitions used in federal government.

Several ongoing health surveillance programs monitor the prevalence in children of developmental disabilities (DD) and conditions associated with it such as intellectual disability (ID), autism spectrum disorder (ASD), cerebral palsy (CP), epilepsy, and spina bifida. As examples, the CDC's Autism and Developmental Disabilities Monitoring (ADDM) network surveillance program generates regularly updated prevalence estimates for ASD, ID, and CP in 8-year-old children and ASD and ID in 4-year-old children. The National Health Interview Survey (NHIS) and the 2016 National Survey of Children's Health (NSCH) are nationally representative population-based surveys that include questions suitable for identifying children with IDD ages 3 to 17 years. Administrative prevalence estimates for IDD in children can be obtained through the National Center for Education Statistics at the United States Department of Education (Fast Facts: Students with Disabilities).

Several administrative data sets and projects provide surveillance data for adults with IDD. For example, an AIDD funded Project of National Significance, the State of the States in Developmental Disabilities (Braddock, Hemp, Tanis, Wu, and Haffer, 2017), provides yearly 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 data from the Centers for Medicare & Medicaid Services (CMS) (Centers for Medicaire and Medicaid Services), the Office of Special Education and Rehabilitative Services (OSERS) at the U.S. Department of Education (OSERS Office of Special Education and Rehabilitative Services), and the Social Security Administration also allow analysts to identify and study people with IDD.

Unlike for children, there are no ongoing national health surveillance systems that monitor the prevalence, characteristics, health needs, and health outcomes of adults with IDD, nor are there data that compare ID with DD. Historically, the 1994-1995 National Health Interview Survey - Disability Survey (National Health Interview Survey) included a comprehensive set of items used by researchers to better understand the child and adult ID and DD populations, including prevalence estimates, general characteristics, health status, and health outcomes. The SIPP Social Security Administration Supplement from 2008 to 2013 included items to identify adult

sample members with ID and/or DD. From 2012 to 2017, the NHIS included an item to identify adult sample members with ID but not adults with DD. Neither the SIPP nor the NHIS surveys currently include data elements sufficient to allow identification of adults with ID and DD.

Addressing the Data Conundrum

Recognizing the need for current surveillance data on children and adults with ID and DD and the challenges to collecting such information, AIDD, in 2015, initiated discussions with a number of federal partners in HHS to explore potential solutions, including the use of NHIS. With pending changes to the NHIS and recent changes to SIPP, there are no national surveys that provide prevalence and health data for people with IDD. These discussions led AIDD to convene a multi-agency, multi-stakeholder meeting in November 2017 with representatives from the 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); 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, one of which was the AIDD National Health Surveillance Workgroup. The charge for this workgroup was to identify existing and suggest new survey questions to supplement the data currently being collected in national survey programs such as the NHIS so that the prevalence of children and adults with IDD could be better estimated.

This technical report is the final product of the AIDD National Health Surveillance Workgroup. This document provides historical context and alternative conceptualizations that underlie approaches to measuring IDD, describes ID and DD using enabling legislation and professional

practice guidelines, and discusses currently available prevalence estimates for IDD in children and adults. This report identifies gaps in current surveillance efforts for adults with IDD and proposes strategies for national survey programs to better identify community-dwelling adults with IDD so that researchers and policy makers have access to data that represent the noninstitutionalized U.S. population. The report is meant to extend beyond the IDD population currently served by Medicaid DD services to include all people with IDD.

The report identifies the key constructs that must be measured to identify sample members with IDD, estimate prevalence rates, and enable current data collection systems to study the health status, outcomes, and unmet needs of this population. These include the minimal questions to be included in population surveys to identify this population, suggests additional domains to fully capture people with IDD for incidence and prevalence estimates, and suggests directions for more comprehensive surveillance of people with IDD. The report closes with a brief review of methodological considerations regarding item development, cognitive testing, and the importance of cultural sensitivity in attending to cultural and linguistic differences within this population to ensure health equity.

Directions for Future Activities:

1. AIDD/ACL and its partners are working with the research staff at the National Center for Health Statistics Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) to construct and cognitively test survey questions that are valid, reliable, and appropriate for people with IDD, including those from racially and ethnically diverse backgrounds. These questions are intended for future use in the NHIS and other surveys to identify respondents with IDD.
2. Once updated and benchmarked, prevalence estimates collected at regular survey iterations can guide future fiscal projections, policy development, and program planning. As statutes are changed, the domains to be measured may need to be updated.
3. Continued collaboration will be needed across federal agencies and stakeholder groups if health surveillance practices are to be broadly implemented across national data

collection systems to enable better identification and prevalence estimates of children and adults with IDD.

4. The representativeness of national surveillance systems will improve if they consistently include people residing in the U.S. territories.

I. Introduction

People with IDD are an important group to identify for government programs and public policy; having an accurate prevalence estimate is important for planning. People with IDD receive significant public and private expenditures intended to support their well-being. Long-term supports and services (LTSS), including both institutional and home and community-based services (HCBS), accounted for 30% of all Medicaid expenditures in 2016, with 28% of all Medicaid-funded supports going to people with IDD (Eiken, Sredl, Burwell, & Amos, 2018). People with IDD also comprise 14% of all working-age Supplemental Security Income and Social Security Disability Insurance beneficiaries (Livermore, 2017).

Public health and policy planning are compromised by the lack of national data on IDD prevalence and the health status of people with IDD. Health surveillance data are essential to allow population health researchers to track the incidence and prevalence of specific populations and to identify characteristics that can influence or contribute to their health (Fox, Bonardi, & Krahn, 2015). Accurate and timely data are critical for federal and state agencies to make projections, establish policies, and implement programs to serve this population. The need for improved health surveillance data for people with IDD has long been recognized. For example, the Surgeon General's report, *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation* (U.S. Department of Health and Human Services, 2002), articulated the clear need to improve health surveillance for people with ID.

A. Estimating the prevalence of IDD

Prevalence estimates of IDD vary based on the operational definitions used and the purposes for data collection. Previous research in the U.S. has reported a prevalence of ID in children of 0.71% to 1.36% (Boyle et al, 2011; Braun et al, 2015), and for ID and/or DD of 1.9% (Larson, Doljanac, & Lakin, 2015 cited in Larson et al 2017). These estimates reach 16.24% when learning disabilities and attention deficit hyperactivity disorder are included in the definition (Boyle et al, 2011). Data from the NHIS-D (1994-1995) indicate the prevalence of IDD in adults to be 0.79% (Larson et al,

2001) to 1.27% (Fujiura & Taylor, 2003), depending on operational definitions used. In the study by Larson and colleagues (2001), the combined prevalence estimates for ID, DD or both in the US non-institutionalized population were 38.2 per 1,000 for children birth to age 5, 31.7 per 1,000 for children ages 6 to 17 years, 7.9 per 1,000 for adults, 14.9 per 1,000 for people of all ages (Larson, et al., 2001). The estimate increased to 15.8 per 1,000 for people of all ages when people with IDD in congregate residential settings were included. The prevalence estimates of IDD among children are typically higher than among adults, likely because of differences in definition, severity of disability, and differences in environmental demands that highlight limitations in some contexts, such as school. In addition, many prevalence studies of DD in children focus on categorical diagnoses such as ASD, or CP rather than on DD as defined by multiple functional limitations (e.g., Boyle et al., 2011; Braun et al., 2015).

Administrative prevalence of IDD can be estimated from data sources including Medicaid administrative claims (ICD 9 and 10 codes), the Medicare Current Beneficiary Survey, National Beneficiary Survey, NCES at the U.S. Department of Education, and Social Security Administration data sets. The characteristics of some individuals with IDD who receive state-level services can be examined through quality assurance programs such as the Medicaid Home and Community Based Services Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey (CAHPS Home and Community Based Services Survey), and the National Core Indicators (NCI).

Administrative data are typically collected to describe recipients of service programs; however, such data sets provide incomplete and potentially misleading information for the purposes of estimating prevalence of IDD and measuring health disparities or unmet needs. For example, a prevalence estimate of 7.37 million people with IDD was obtained for 2016 using prevalence estimates based on the 1994-1995 NHIS-D, combined with the 2016 census data and estimates of people in congregate settings. However, only 20% of these people with IDD received services through state-level DD programs (Larson et al, 2018). This discrepancy indicates that administrative data, when collected, only captures a fraction of all people with IDD. It should be noted that while administrative data on IDD are currently collected by all states, the District of

Columbia, and Puerto Rico, they are not collected by the other U.S. territories, making such administrative data sets inadequate to estimate prevalence of IDD in all the U.S. states and territories.

B. Impetus for this report

Recognizing the need to establish better surveillance methods led AIDD to convene a multi-agency, multi-stakeholder meeting in November of 2017 to explore issues and possible remedies for this information gap.

Participants included representatives from the following HHS federal agencies:

- Administration on Community Living (ACL)
- Centers for Disease Control and Prevention (CDC)
- Assistant Secretary for Planning and Evaluation (ASPE)
- Centers for Medicare & Medicaid Services (CMS)
- Office on Minority Health (HHS)

and national disability organizations:

- Association of University Centers on Disabilities (AUCD)
- Center for Epidemiological Research for Individuals with Intellectual and Developmental Disabilities (CERIIDD)
- Human Services Research Institute (HSRI)
- National Association of Councils on Developmental Disabilities (NACDD)
- National Association of State Directors of Developmental Disabilities Services (NASDDS)

The stakeholder meeting also included university-based researchers from nine different programs that focus on health surveillance and IDD. Subject matter experts from the following universities and centers participated: Cincinnati Children's Hospital Medical Center, Georgetown University, Ohio State University, Oregon State University, University of Illinois at Chicago, University of Colorado, University of Kansas, University of Minnesota, and University of New Hampshire.

Through presentations and structured discussions, participants reviewed the status of health surveillance for people with IDD, available prevalence estimates, expected changes to data availability based on design changes to the NHIS, and strategies for improving health surveillance for adults with IDD. AIDD and meeting participants agreed on the potential value of further investigation in two directions: (a) prevalence data from national surveillance and (b) richer contextual information from administrative data at the state, territory, and multi-state level.

With an overarching goal to prioritize and address the need for better data to understand the prevalence, health status, and health determinants of people with IDD, two workgroups were formed. The specific charge for the AIDD National Health Surveillance Workgroup:

> "(To collaborate with NCHS) to develop criteria/guiding principles and identify existing or draft additional (1-3) question(s) for use with the revised NHIS and other national surveys to identify persons with intellectual and developmental disabilities in order to determine prevalence of IDD (denominator).

II. Background

A. Historical and legislative context in the U.S.

While people with IDD have always been part of American society, advocacy efforts beginning in the early 1960's brought increased national attention to their situations (Braddock & Parish, 2001; Bersani & Lyman, 2009). Since that time, the understanding of IDD within the social context has continued to grow and change. Terminology has changed, diagnostic practices have advanced, the nature of services and supports have continued to evolve, and technology has changed many aspects of life. Indeed, our very understanding of IDD has changed, along with increased societal expectations for richer, more participatory, and self-directed lives for people with IDD. For example, changes in our understanding and diagnosis of disabilities such as ASD have influenced the prevalence of IDD in ways that are not yet fully understood. ASD was once thought to be a very rare condition; however, data from the 2014-2016 NHIS indicated ASD occurs in 24.7 children per 1,000 (Zablotsky et al, 2017). As the field of medicine has advanced, the development of effective medical interventions has reduced the impact of or even prevented ID due to specific preventable causes such as iodine deficiency and phenylketonuria (World Health Organization, 1998).

The U.S. federal government has historically provided various sources of support for the IDD population. In 1965, the Medicaid program was introduced, offering federal funding through a partnership with states to provide services to certain low-income people, including some people with disabilities. Subsequently, Medicaid-funded Intermediate Care Facilities for Individuals with Intellectual Disability (ICF-ID, previously ICF/MR) facilities spurred state investments to reduce overcrowding and provide appropriate services to people with IDD in institutions. In 1981, Congress passed a law that permits states to expand services in community-based settings through the use of Medicaid HCBS waivers.

In addition to the Medicaid program, the federal government also provides educational services and supports for people with IDD. The Education for all Handicapped Children law 20 U.S,.C, § 1400 et seq, passed in 1975 guarantees a free and appropriate public education for all students regardless of the type or severity of their disability. The Rehabilitation Act of 1973 prohibits discrimination against people with disability in federally-funded services. The Americans with Disabilities Act (ADA), passed in 1990, prohibits discrimination based on disability in all areas of public life. As the above legislation have been reauthorized and updated by Congress, and public policies 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.

Also rooted in the U.S. social fabric are the cultural views and biases, both implicit and explicit, regarding people with IDD (Scior, 2011; Werner, Corrigan, Ditchman & Sokol, 2012). Racial and ethnic biases in the U.S. have additionally impacted how people with IDD 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 targeted by current efforts to address health equity within HHS (OMH U.S. Department of Health and Human Services Office of Minority Health).

The majority of people with IDD live with their families and caregivers in their homes or in other home and community-based settings. There were an estimated 7.37 million adults and children with IDD in the U.S. in 2016 based on calculations using IDD prevalence rates from the 1994-95 NHIS for adults, the 2016 NHIS for children, the 2016 U.S. Census, and data on people with IDD living in congregate settings in 2016 (Larson et al., 2018). In 2016, an estimated 1.49 million

people with IDD (20% of the estimated 7.37 million IDD population) were known to state IDD agencies, and 1.23 million (17%) received Medicaid- or state-funded long term services and supports (LTSS) administered by state IDD agencies (Larson et al, 2018). Of those receiving funded supports, 58% lived with a family member, and most of the rest lived in a home or community-based setting shared by six or fewer people with IDD. While administrative data can be used to understand the characteristics and needs of current service recipients with IDD, data based on the U.S. noninstitutionalized population are needed to fully count the IDD population as well as understand their health status, health disparities, health outcomes, and residential circumstances.

B. Conceptualizations of disability

The concept of disability has evolved over the past century (Iezzoni & Freedman, 2008), with changing conceptualizations reflected in changing definitions in federal statutes. During much of the 20th century, experts considered IDD within a medical model, which views disability as a health problem arising directly from disease, trauma, or medical condition, with the disability residing within (or as a trait of) the individual. The medical model's perspective is that the person's condition or difference results in the individual's inability to function (Iezzoni & Freedman, 2008). The use of diagnostic categories to classify disabilities is founded in the medical model.

The independent living and civil rights movements, focused attention on those external forces as sources of limitations (such as social and environmental circumstances). The social model views disability as a condition resulting from the demands or expectations of the social environment, including how the society is organized, prejudice, physical and attitudinal barriers, and discrimination (Mont, 2007). The social model of disability views social policies as the solution to disability, in particular policies that direct change 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 (ICF) (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).

Changes in federal laws, both enacted by Congress and as interpreted by the U.S. Supreme court, have greatly impacted the concept of disability within the last 20 years. The Americans with Disabilities Act (ADA) was first passed in 1990 (42 USC *§* 12101 *et seq*.) and the ADA as Amended (42 USCA *§* 1201 *et seq*.) passed in 2008; both describe the purpose of the ADA to be a national mandate for the elimination of discrimination against individuals with disabilities (42 USCA *§* 12101 2(b)(1)). The ADA defines disability as "a physical or mental impairment that substantially limits one or more major life activities of such individual," "a record of such an impairment," or "being regarded as having such an impairment." As civil rights legislation, the ADA defines disability broadly to encompass physical and mental impairments and prohibits discrimination against people with disabilities. The ADA further established the civil rights of individuals with disabilities to full participation in society by mandating reasonable accommodations as a strategy to enable their full participation. In June 1999, the U.S. Supreme Court further clarified the ADA in its decision in *Olmstead v. L.C., 527 U.S. 581,* concerning the right of people to live and participate in community-based settings.

C. Defining intellectual and developmental disabilities

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). In general, the definitions used for ID and DD are consistent with professional practice and federal

legislation as contained within the DD Act. Because these definitions require significant functional limitations, they exclude some people who are not severely limited by their condition.

The DD Act had its origins in 1961, which in turn contributed to the Maternal and Child Health and Mental Retardation Planning Amendments of 1963 and the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963. In subsequent years, legislation and definitions were updated as society's understanding of IDD changed.

In passing the latest iteration of the DD Act, Congress acknowledged the significance of the concept of function and full participation in society when it noted in its finding that:

> *". . disability is a natural part of the human experience that does not diminish the right of individuals with DD to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society" (emphasis added).* 42 U.S.C. §15001(a)(1).

i. Developmental Disabilities

This paper uses the definition of DD promulgated in the DD Act o (42 U.S.C. §15001 et seq.), that is,

> "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; receptive or expressive language; learning; mobility; self-direction; capacity for 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."

ii. Intellectual Disability

While ID is not defined in federal statute, the U.S. Supreme Court and federal entities such as ACL and the President's Committee for People with Intellectual Disabilities (PCPID) within HHS recognize the American Association on Intellectual and Developmental Disabilities' (AAIDD) definition of ID as "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 limitations in intellectual functioning is operationally defined as an IQ score that is approximately two standard deviations below the mean (Schalock et al, 2010). As one standard deviation is 15 points below the mean of 100 for most standardized intelligence tests, two standard deviations below the mean would be an IQ score of approximately 70.

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, 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 are activities of daily living (personal care), 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 that is 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.

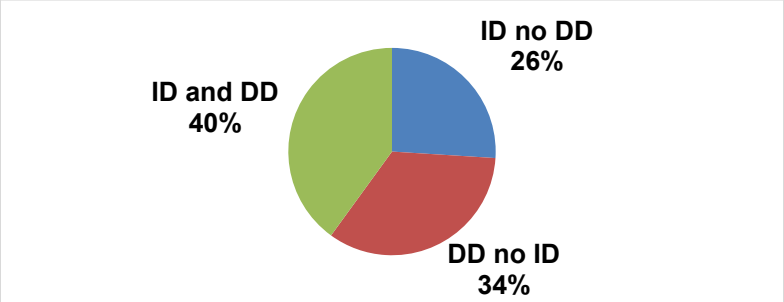
The term used to refer to people with ID has evolved over time as older terms (most recently mental retardation) acquired negative connotations and became offensive to many people. In

2010, with the passage of Rosa's Law (Pub. L. 111-256), references to "mental retardation" in federal laws were replaced with the term intellectual disability. This legislation substituted one term for another, but did not change eligibility determination or programming.

iii. Comparing ID with DD

While ID is typically regarded as one type of DD, the two conditions do not overlap perfectly when the definition of DD is based on the DD Act. If a person with ID does not experience substantial limitations in three or more specified life activities, they will not meet criteria for DD as outlined in the DD Act. Larson et al. (2001) analyzed the NHIS-D (1994/95) data to compare survey members who met criteria for ID, for DD, and both. Among adults, 40% of individuals with IDD were identified as having both ID and DD, 26% were identified as having ID but not DD because they had significant limitations in only two areas of major life activities (intellectual functioning/learning and one type of adaptive behavior) but not three or more, and 34% were identified as having DD but not ID because learning was not one of their three substantial functional limitations (See Figure 1).

Figure 1. Adults in the NHIS-D with Intellectual Disability, Developmental Disabilities, or Both.



Data Source: Larson et al., 2001

Appendix A provides an overview of the domains of ID and DD as defined by the DD Act.

D. Past approaches to measuring IDD

i. Function vs. Diagnosis

Data collection about people with IDD varies greatly, and may utilize either diagnostic conditions, functional limitations, or both. For example, many health care services, medical care reimbursement, and rehabilitation research 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.). In the absence of a cohesive approach in conceptualization and measurement of ID and DD, this remains a challenge for interoperability across federal agencies.

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 narrower views of disability that emphasize either the condition of the person or the consequences of a condition. This approach is usually operationalized as a question 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?"). In 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?").

ii. Single Questions or Multiple Question-Sets

Of the few recurring population-based or administrative data systems that screen for ID or DD, most employ a single item about the presence of ID or DD as a condition (Bonardi et al, 2011). Notable exceptions, prior to their redesign, were the NHIS and SIPP; however, capturing the nature of a multidimensional view of IDD typically requires more than a single question that indicates inclusion or exclusion from a group. The reliability and validity of survey-based IDD identification improves as the number of questions increases. For example, IDD identification using a condition-based screen ("Do you have IDD?") versus a cause of limitation question ("Is IDD the primary cause of the limitation?") in the NHIS and SIPP resulted in overlapping but not totally congruent samples. Further, when using a single question on the cause of limitation as ID in the 2000 NHIS, and comparing this with the combination of questions available to identify mental retardation [sic] in the 1994-95 NHIS-D, Hendershot, et al (2005) identified only one-third the size of estimated people with ID. The optimal number of questions, and their content and wording are yet to be determined, but it is clear that more questions will provide more precision and multidimensionality.

iii. Self-and Proxy-Reporting

A further challenge for survey construction is the reliance on inter-changeable self- and proxy-reporting. In the 2001-2002 NHIS Adult Survey, proxy responses were used for 59.3% of adults with ID 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, close family members' proxy-responses are more aligned with self-report than professional report; and questions related to internal experiences are at greater risk of discordance. Finally, whether by self- or proxy-report, stigma and related reluctance to disclose limitations in intellectual and developmental functioning are suspected to contribute to under-reporting.

III. Surveillance Gaps and Strategies for Identifying IDD Respondents in Population-Based Surveys

To address its charge, the workgroup sought to investigate and answer several key questions:

a) Do recently adopted standard question sets on disability enable identification of people with IDD?
b) Are data available for adults with IDD as well as children with IDD?
c) What content domains are present in the revised NHIS 2019 survey and what additional domains are needed for identification of people with IDD?
d) What existing questions are available from other surveys in needed content domains?
e) What additional methodological considerations are needed?

A. Limitations of current disability identification questions

Past efforts to establish a unified framework for disability statistics led a number of federal data collection efforts to include a standard set of questions on functional limitations in basic and universal domains of activity (e.g., seeing, hearing, mobility, cognition, and self-care).
The development of the ACS disability question set, a set of six questions that ask about difficulty with seeing, hearing, mobility, cognition, self-care and independent living using a yes/no response (United States Census Bureau) (U.S. Census Bureau), has enabled people with disabilities to be identified in several U.S. population-based surveys (e.g., ACS, CPS, SIPP); however, it is not possible to identify people with IDD using this question set.

The NHIS uses a slightly different set of six disability identification questions: the international standard, known as the Washington Group Short Set (WG-SS) (Madans, Loeb, & Altman, 2011). The WG-SS captures information on difficulty with seeing, hearing, mobility, cognition, self-care and communication using a continuum of response options in order to capture severity (The Washington Group Short Set of Questions on Disability). One functional domain common to both question sets is cognition. An ACS question asks about “serious difficulty concentrating, remembering, or making decisions,” while the analogous WG-SS question asks about “difficulty

concentrating or remembering." People who report this type of difficulty have a wide array of conditions, including dementias such as Alzheimer's disease, stroke and traumatic brain injury, schizophrenia or other mental health conditions, and health conditions requiring medications that affect cognition. Unfortunately, a single question on cognition does not provide sufficient information to differentiate between people with IDD and those with other conditions.

B. Available survey data for adults and children with IDD

i. Adults with IDD in the U.S.

Only three peer-reviewed studies using the NHIS-D data published since 2000 report prevalence of ID and/or DD in U.S. adults, and none of these were published after 2015. One study using NHIS-D (1994-95) data reported an adult prevalence rate of 7.8 per 1,000 for ID, DD or both and an all-age prevalence rate of 14.9 per 1,000 (Larson et al, 2001). A second study with NHIS-D (1994-95) data estimated the prevalence of ID, including mild intellectual impairments (impairments not severe enough to meet the AAIDD threshold), to be 12.7 per 1,000 (Fujiura & Taylor, 2003). A study using the 2008-2012 SIPP data estimated the prevalence of IDD for children and adults 6 years or older to be 10.3 per 1,000 (Burke & Fujiura, 2013). International estimates for adults with ID across a range of countries and data sets are approximately 10.37 per 1,000 (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011; McKenzie, Milton, Smith, & Ouellette-Kuntz, 2016), with Western Australia using multiple data sources reporting prevalence as 17.0 per 1,000 (Bourke, et al, 2016).

Only two peer-reviewed studies are available which analyzed prevalence rates of IDD in U.S. adults by race and ethnicity. Using ten years of linked NHIS and Medical Expenditure Panel Survey (MEPS) data (2002-2011), Fujiura, Li, and Magaña (2018) found higher rates of IDD among Black Americans (14 per 1,000) and nearly identical rates among White (9 per 1,000) and Hispanic Americans (8.2 per 1,000). An earlier study (Fujiura & Yamaki, 1997) reported a similar pattern for prevalence by race and ethnicity using 1990-1991 SIPP panels for children and adults aged 3 and older.

A Native American developmental disabilities needs assessment published in 2012 revealed that there are no national IDD prevalence data specific to the American Indian/Alaska Native populations (AI/AN). The AI/AN populations have the highest rate of general disability in the U.S., with 27% of working age adults and 7.7% of children having a disability. For comparison, the rates of general disability for non-Hispanic white are 16.2% for adults and 5.7% for children (Cohen, et al 2012).

An entire generation of children with severe lifelong disabilities finished school and transitioned into adulthood since the 1994-1995 NHIS-D was fielded. Aside from the National Longitudinal Transition Study 2, which followed recipients of special education who were in 7th grade or above in 2000 for up to eight years after graduation (Newman et al., 2011), very little is known about the noninstitutionalized adult population with ID and DD.

ii. Children with IDD in the U.S.

Unlike the paucity of studies about adults, children with ID and DD are identifiable in several ongoing public health surveillance efforts. Between 2000 and 2018, at least 35 studies were published reporting prevalence rates for ID and DD in children. A study using the 2011-2013 NSCH estimated that the prevalence of ID in children 3 to17 years old was 1.26% (Maenner, et al., 2016). A study using the 2014 NHIS estimated prevalence rates for children ages 3 to 17 years of 1.14% for ID, 2.76% for ASD, 4.55% for other developmental delays and 6.99% for one or more of these conditions (Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). The prevalence of ID, DD, ASD, and Down syndrome in children has increased dramatically since 1995. It is unknown how much of this measured increase relates to increases in awareness, changes in definition, increased longevity, changes in prevalence or other factors.

The number of people in the US with Down syndrome quadrupled from 49,923 in 1950 to 206,366 in 2010 (de Graaf, Buckley, & Skotko, 2017) while the country's overall population size doubled from 152.3 million to 309.3 million during that same time. The proportion of children

aged 6 to 17 years receiving special education in 2017 was 0.73% for ID, 1.03% for ASD, 0.22% for multiple disabilities, and 0.26% for developmental delay (2.45% for the four categories combined) (ED*Facts* Data Warehouse, 2017; NCES, 2017). While studies from the 1990's showed substantially higher prevalence estimates for children compared with adults, little is known about whether this continues to be true today.

Several studies have documented differences in IDD prevalence rates in U.S. children across race and ethnicity. An analysis of NHIS data from 1997-2008 (Boyle, et al, 2011; Blumberg, 2012) revealed that compared to White children, Black children were 1.7 times more likely to be identified with ID and equally likely to have DD, while Hispanic children were significantly less likely than White children to be identified to have DD (odds ratio [OR] = .7) and equally likely to have ID (OR = 1.1). While there are no prevalence estimates for IDD among AI/AN children, of the AI/AN children in tribal-operated schools or schools that are operated by the Federal Bureau of Indian Education, 21% were in special education compared to 13% of all U.S. public school students (Cohen, et al, 2012).

The workgroup considered the data available for children and adults in the current NHIS and other national surveys. While data to identify children with IDD were considered generally adequate, significant concerns were raised around the need for current data on adults. The workgroup strongly recommended that there be a priority on including questions for identification of adults with IDD in national surveys.

C. Domains required to identify ID and DD

i. Domains Required by the Definitions of ID and DD

Using the DD Act definition for DD and the AAIDD definition for ID, the workgroup first reviewed current population survey programs that measure some or all of the domains needed to identify sample members with IDD. The workgroup also identified domains not currently included in U.S.

population-based surveys that are needed to identify people with IDD. The 2016 NHIS survey (before the current redesign) included items covering limitations in five of the seven DD Act major life activity areas (communication, self-care, capacity for independent living, economic self-sufficiency, and mobility), but did not include items to assess limitations in learning, self-direction, age of onset, or expected duration of limitations. Table B1 in Appendix B lists the 2016 NHIS items in these five areas by subscale.

Table 1 below describes the essential domains for identifying ID and DD and their presence or absence in the 2019 NHIS. These domains are derived from the AAIDD definition of ID and the DD Act definition of DD.

Table 1. Essential domains to identify ID and DD.

Major life activity domain	Intellectual Disability	Developmental Disabilities	Construct captured in redesigned NHIS
Intellectual functioning	√		
Adaptive Behavior			
Conceptual skills			
Learning (academics)	√	√	
Self-direction		√	
Practical skills			
Self-care	√	√	√
Independent living skills	√	√	
Economic self-sufficiency	√	√	√
Social skills			
Communication	√	√	√
Mobility		√	√

Other criteria	Intellectual Disability	Developmental Disabilities	Construct captured in redesigned NHIS
Age of onset	√ (Before age 18)	√ (Before age 22)	
Severity	√	√	√
Lifelong duration		√	

While the essential domains for ID and DD certainly overlap, it is clear that adaptive behavior constructs named in the ID definition were broader in scope. For example, significant deficits in *practical skills* is one element of the ID definition. Although practical skills are not mentioned by name in the DD Act, the discrete components of practical skills including self-care, independent living skills, and economic self-sufficiency are essential major life activity domains in the DD Act. Table 1 provides a list of essential skills and abilities to identify ID and DD where discrete skills are indented under the conceptual domains. Check marks indicate the elements that are essential to a diagnosis of ID or DD and the final column indicates whether or not the construct is measured in the 2019 NHIS. One point of discussion among committee members had to do with the lifelong duration criterion. While the AAIDD definition of ID certainly conceptualized ID as a lifelong condition, duration was not named nor is it assessed to establish a diagnosis of ID. In contrast, the DD Act explicitly named lifelong duration as a criterion. Therefore, lifelong duration is checked as essential for DD and not ID in Table 1.

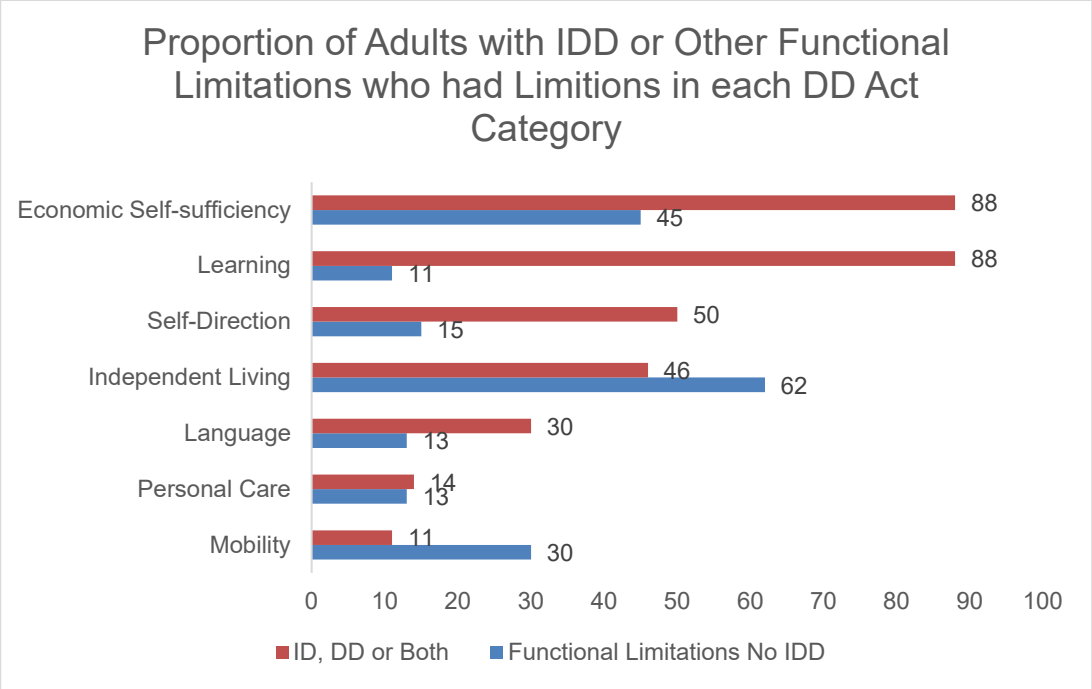
The redesigned 2019 NHIS measures some of the domains needed to identify people with IDD, specifically mobility, communication, self-care, and economic self-sufficiency. In addition, the 2019 NHIS includes items on social participation which, while not currently a DD Act criterion, could be considered for addition in future DD Act reauthorizations based on current understanding of the importance of social participation to health and human function. Criteria for the DD Act definition of DD which are not included in the 2019 NHIS are the domains of learning, independent living, and self-direction, as well as age of onset (before 22 years), and projected duration of the limitation (lifelong or extended duration). Criteria for the AAIDD definition of ID that are not addressed in the 2019 NHIS are the domains of intellectual functioning, conceptual skills, social skills, and age of onset (before age 18). Elements needed to identify DD that are missing from the 2019 NHIS include independent living skills, self-direction, and age of onset (before age 22). In summary, the 2019 NHIS does not address intellectual

functioning, conceptual skills, social skills, independent living skills, self-direction, age of onset, or projected duration of the limitation.

ii. Domains that Best Predict IDD Status

When data from the NHIS-D (1994-95) were analyzed to identify the items that best discriminate between survey participants who had IDD and those who had functional limitations but not IDD, differentiating characteristics could be identified (Doljanac, Larson, & Lakin; 2004). Figure 2 shows the domains that contributed to the identification of adults with IDD. In a series of logistic regression analyses, once sex, age, health status, race, and economic status were considered, adults who met criteria for ID or DD were more likely than adults with other functional limitations to have significant functional limitations in learning (OR =46.85), economic self-sufficiency (OR = 8.38), communicating with family (OR = 8.64) or with non-family (OR = 8.04), self-direction (OR = 6.01), difficulties understanding others (OR = 5.09), and personal care (OR = 2.90). These findings further informed the workgroup's item development considerations.

Figure 2. Proportion of adults with IDD and adults with other functional limitations across areas of function (NHIS-D 1994-1995).



Based on the above findings, the workgroup identified the following priority areas to consider for item development and testing for future national surveys, in addition to those in Table 1:

- Learning
- Independent Living
- Age of Onset

D. Questions from other surveys that assess needed domains

Because the current NHIS does not include a sufficient range of items to identify the IDD population, the workgroup examined former population survey questions as potential sources of questions to identify adults with IDD for future NHIS and other national surveys.

i. Survey of Income and Program Participation (1984-2013)

The SIPP is a national survey program of the non-institutionalized civilian population in the U.S. including Puerto Rico, begun in 1984 and conducted annually by the U.S. Census Bureau. The

2008-2013 SIPP was notable for its extensive disability and function modules, which included more than 90 questions focused on health status, activity and functional limitations, activities of daily living (ADLs) and Instrumental Activities of Daily Living (IADLs), the presence of specific impairments and medical conditions, age of onset and duration, need for assistance, and conditions that were considered the primary reason for limitations. There were separate items for adults, children, and very young children. The 2008-13 Panel was the final implementation of an extended disability topical module. With the 2014 redesign of the SIPP, a smaller set of disability questions was used that focused solely on functioning rather than type of impairment, and as a result people with IDD cannot be identified.

The general approach and question structure of the disability module from the SIPP may be informative for future IDD survey question development. Appendix B, tables B1 and B2, summarize items used to identify adults and children with IDD, respectively. Two groups of items from the 2008-2013 SIPP are represented. For the first group of items, if a respondent acknowledged a limitation or difficulty, he or she was asked to identify from a list the condition or conditions that caused the difficulties. Mental retardation [sic]and cognitive impairment [learning disability] were options). The second group of IDD screening questions was a direct query asking the respondent if they had mental retardation [sic]or a developmental disability or related condition. The analyst could base identification on respondent or proxy identification as having ID, DD, or other combinations, as well as include functional and activity limitation conditions in the identification.

ii. National Health Interview Survey - Disability Survey (1994-1995)

The NHIS-D was a one-time supplement to the NHIS. Prompted by awareness of the need for better policy-relevant data on disabilities, 11 federal agencies—along with the Robert Wood Johnson Foundation—collaboratively planned and funded the NHIS-D which was conducted in two phases in 1994 and 1995. In the NHIS-D, adults were identified as having DD if they had substantial functional limitations in at least three of the seven DD Act areas (self-care,

communication, learning, mobility, self-direction, independent living, and economic self-sufficiency), the difficulty began before age 22, and the limitation was expected to continue for at least 12 more months (See Table B2 in Appendix B for more details). Adults could be identified as having ID if they reported having (a) mental retardation[sic], (b) an ICD code (i) indicating ID as a cause of limitations in learning, communication, getting along with others, activities of daily living, instrumental activities of daily living, or work, or (ii) listing the condition as a reason for a health care visit, or (c) having a learning disability AND a related condition such as CP, Down syndrome, spina bifida, autism, or hydrocephalus AND had completed no more than 14 years of education (2 years of post-secondary education).

iii. Essential Domains to Identify IDD for Health Surveillance

a. Learning

The workgroup concluded that without survey items to capture intellectual functioning or functional limitation in learning, it will not be possible to identify adult sample members with IDD. The workgroup identified several items used for leaning in other surveys that could be tested for this purpose in the table below. It is noted that several of the items used in other surveys are diagnosis-based.

Table 2. Learning questions from other surveys.

Survey	Questions
NHIS-Child (2012)	Ever told by doctor or other health professional that you have an intellectual disability?
NHIS-Child (2012)	Ever told by doctor or other health professional that you have autism spectrum disorder?
NHIS-Child (2012)	Ever told by doctor or other health professional that you have another developmental disability?
SIPP (2008-2013)	(1) Does _____ have (a) A learning disability such as dyslexia? (b) Mental retardation? (c) A developmental disability such as autism or cerebral palsy?
NHIS-D (1994-1995)	_____ has serious difficulty learning how to do things most people their age can learn?
WHODAS 2.0 (2010)	In the last 30 days how much difficulty did you have in: • Analyzing and finding solutions to problems in everyday life • Learning a new task, for example, learning how to get to a new place
Ohio Medicaid Assessment Survey (2017)	Do you have a developmental disability?
Diagnostic Adaptive Behavior Scale (DABS) (2017)	If you attended school, did you receive special education?
Diagnostic Adaptive Behavior Scale (DABS) (2017)	Did you have significant difficulties learning in school or to read or write?

b. Independent Living Skills

Independent living skills are an essential construct in the definitions of ID and DD, yet this domain is not addressed in current population surveys. The following items used to measure independent living may inform item development.

Table 3. Independent living questions from other surveys.

Survey	Questions
American Community Survey (2017)	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?
Health and Retirement Study (2016)	Because of a health (or memory) problem do you have any difficulty with • Dressing, including putting on shoes and socks? • Bathing or showering? • Eating, such as cutting up your food? • Getting in or out of bed? • Using the toilet, including getting up and down? • Using a map to figure out how to get around in a strange place? • Prepare hot meals? • Shopping for groceries? • Making phone calls? • Taking medications? • Managing your money -- such as paying your bills and keeping track of expenses?
Health and Retirement Study (2016)	Did anyone help by supervising [him/her] to ensure safety, provide reassurance, or to make sure that nothing went wrong?
Health and Retirement Study (2016)	Do you get any help with work around the house or yard because of a health problem?
NHIS-D (1994-1995)	Do you need help from another person for the following activities or does someone else always do this for you because you cannot (each activity asked as its own question) • Preparing meals • House cleaning • Handling money • Shopping for yourself • Medication management • Going somewhere/independently accessing transportation • Being home alone for 2 or more hours

c. Age of Onset

Both ID and DD are conceptualized as lifelong conditions that are first apparent during the developmental period; however, the AAIDD definition of ID operationalizes this onset as before the age of 18 while the DD Act operationalizes this onset as before the age of 22. The redesigned NHIS does not assess whether specific limitations were apparent during the developmental period nor does it assess the expected duration of particular limitations. The workgroup discussed several possible strategies to assess age of onset and expected duration in national surveys, and determined that, given survey constraints, it would not be necessary to ask about age at onset for every functional limitation item. Rather, when a respondent indicates that they have a substantial limitation (e.g., have a lot of difficulty or are unable to do) in any of the qualifying conditions or limitations, a single follow up question should be asked to determine if the limitation first occurred before the person was 22 years old.

iv. Additional Domains Needed for IDD Prevalence Estimates

In its deliberations, the workgroup identified areas to consider for future item development that might be added to the NHIS or other national surveys. These areas are not comprehensive, but arose in the workgroup's discussion of item sets that could inform prevalence research. In addition to the minimum item set (learning, independent living, and age of onset), major life activity domains to consider for future item development include:

a. Communication

Functional limitations in communication is a domain specified in the DD Act, and communication is a type of adaptive behavior under the AAIDD definition of ID. The 2016 NHIS included only one item on difficulty communicating. The following items to measure communication are provided in the figure on the next page.

Table 4. Communication questions from other surveys.

Survey	Questions
WG-SS (2002)	Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?
NHIS-D (1994-1995)	Because of a physical, mental or emotional problem, the person has a lot of difficulty or is unable to use a telephone
NHIS-D (1994-1995)	Person has serious difficulty communicating with people outside of the family.
NHIS-D (1994-1995)	Person has serious difficulty understanding others when they talk or ask questions.
WHODAS 2.0 (2010)	In the last 30 days how much difficulty did you have in: • Generally understanding what people say • Starting and maintaining a conversation

b. Self-Direction

The health surveillance intent of identifying survey respondents with limitations in autonomous decision-making, in conjunction with other data, would be to better estimate the prevalence of people with DD. A review of the literature on self-direction and self-determination was conducted to explore possible survey items to measure self-direction. The workgroup used "self-direction" to refer primarily to personal capacity or functional ability to make their own free choices, consistent with the construct of major life activities outlined in the DD Act. "Self-determination," on the other hand, was used in the DD Act to refer to control over those activities and environmental supports that offer opportunities to communicate choices and exercise control over their lives (DD Act). As noted by Mumbardo-Adam and colleagues (2017), self-determination requires "both personal capacities and environmental opportunities" (Mumbardo-Adam, et al, 2017).

Despite great efforts, the workgroup identified little literature to inform this issue. Indeed, the workgroup concluded that it is difficult to conceptualize the ability to make choices apart from the ability to understand and/or communicate choices, and the ability to self-direct also depends, to a large degree, on having the opportunity to exercise choices.

CMS uses "self-direction" to indicate that HCBS recipients or their representatives have decision-making authority over certain services and responsibility to manage them with the assistance of a system of available supports (CMS, n.d.). Such a model is an alternative to traditionally delivered and managed services, such as an agency delivery model. Most Medicaid self-directed programs allow states to convey employer authority and budget authority to Medicaid beneficiaries, often in the provision of personal care and other HCBS services. Employer authority permits Medicaid beneficiaries to manage their own direct service staff in terms of determining the requisite skills and training, and to hire, fire, and supervise staff. Budget authority permits beneficiaries to allocate their HCBS budget, which could include setting the hourly wages for their staff. Fiscal intermediaries may be used to ensure accounting for their worker's wages, benefits, and other items within the budget.

Medicaid and other publicly-funded LTSS programs use a variety of tools to assess the extent to which their beneficiaries are receiving services that support self-determination. Tools currently available for this purpose include HCBS CAHPS survey, the Council on Quality and Leadership's Personal Outcome Measures, and the National Association of State Directors of Developmental Disabilities Services' (NASDDDS) NCI.

For the current purposes, however, the goal is not to assess whether people receive services supportive of self-determination, nor is the goal to examine any specific Medicaid service delivery models. Rather, the workgroup considered what survey items could be used to identify people with limitations in autonomous decision-making. In light of the difficulty in isolating items to measure self-direction (and disentangling it from the opportunity to exercise choice), the workgroup concluded that additional conceptual work was needed on the construct. The following items were used in NHIS-D to measure self-direction; however, they do not disentangle ability from opportunity.

Table 5. Self-direction questions from other surveys.

Survey	Questions
NHIS-D (1994-1995)	Because of a physical, mental or emotional problem the person needs to be reminded or have someone close by for • Eating • Bathing • Dressing • Using a toilet • Transferring in and out of bed
NHIS-D (1994-1995)	Do you have a court appointed representative currently authorized to make decisions on your behalf such as a guardian, conservator, power of attorney, or medical proxy?
NHIS-D (1994-1995)	If you do not live with a family member, did you choose the place you are living?
NHIS-D (1994-1995)	Do you decide what to wear, how to spend your money, when to eat, and when to go to bed?
NHIS-D (1994-1995)	Lives with a family member as an adult
NHIS-D (1994-1995)	Had proxy respondent because of a disability

c. Expected Duration

Both ID and DD are conceptualized as *lifelong condition*s that are first apparent during the *developmental period*, and for which the impact of the conditions can be reduced through the *application of supports.* The DD Act definition specifies that the condition will continue indefinitely and require ongoing services and supports. AAIDD notes that with appropriate personalized supports over a sustained period, the life functioning of the person with ID generally will improve (Schalock, 2010). While the workgroup recognized that expected duration is an important consideration for physical limitations (where limitations following an injury are less likely to be enduring), this is less of a concern with ID and DD that are less transitory in nature. The workgroup concluded that “expected duration” was a less pressing priority than others for developing questions for future identification of people with IDD.

IV. Methodological Considerations

Appropriate and rigorous surveillance work in IDD requires attention to many methodological details. The workgroup endorsed the following four methodological considerations to be the most relevant for its purposes: small sample size, benchmarking the prevalence of ID and DD from 2015 and beyond (to align with the data requirements of the HHS *Healthy People* initiative), developing and cognitively testing items, and producing comparable measures across culture, language, race, and ethnicity. Each are briefly discussed below.

A. Small sample sizes

The low prevalence of IDD in the U.S. population results in small sample sizes (along with other barriers to surveying this population) in virtually all national surveys. A strategy commonly used by researchers is to pool data across multiple years (e.g., Dixon-Ibarra & Horner-Johnson, 2014). This requires that the same question(s) are repeated across multiple years. The workgroup recognizes that, even with pooling across years, the small sample sizes constrain the types of analyses that are possible. Another strategy to increasing the sample size would require oversampling in specific years.

B. Benchmarking

Several sources can provide benchmark estimates of the number of people with IDD in the United States, including public health surveillance, administrative data, and nationally representative surveys. The federal partners are currently working together to determine the number of years of data that will best benchmark a current national prevalence rate of IDD. The current collaborative thinking is that three years of survey data from the NHIS to extrapolate IDD data will give an accurate benchmark for overall prevalence that can be used for future regular intervals of IDD prevalence. Each data source uses different methods to identify individuals and produces different prevalence estimates. Thus, it is important to note which segments of the

population are included and excluded (i.e., age, type of disability), and whether there is adequate sampling for race and ethnicity when considering estimates for benchmarking.

C. Item development and cognitive testing

The workgroup collaborated with the National Center for Health Statistics (NCHS) to learn about the types of information needed to develop and cognitively test items for possible inclusion in the NHIS. The Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) at NCHS develops and cognitively tests a variety of questions for inclusion in data collection activities. The CCQDER has conducted multiple rounds of cognitive testing of function questions for both children and adults for, among others, the Washington Group and the United Nations Children's Fund. The CCQDER testing has demonstrated the difficulties associated with developing questions to identify substantial functional limitations in learning for adults. Similarly, translating the concept of self-direction into a viable survey measure for research purposes has been difficult.

The workgroup suggests continued collaboration with NCHS' CCQDER to conduct development and cognitive testing of those constructs identified as important but missing in validated survey items. This collaborative work conducted with the CCQDER would include addressing the known issues associated with the prior work in these constructs as well as potential development of new items.

D. Including racial ethnic, and linguistically diverse populations

Title VI of the Civil Rights Act of 1964 states: "No person in the United States shall, on the grounds 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 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 incorporates a sampling frame that contains these populations and, ideally, oversamples for underrepresented racial, ethnic and linguistic minority 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; USHHS, 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 both racial and ethnic groups 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; HHS, n.d.) 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.

E. 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, ACS, and SIPP, the omission of the other U.S. territories from most population-based surveys and the NHIS limits the ability to estimate prevalence and understand health outcomes of all Americans with IDD.

V. Summary and Conclusions

There is a compelling need for timely and accurate information on this important population. Changes to national health surveillance systems provide a challenge and an opportunity. The AIDD National Health Surveillance Workgroup is proposing a path toward a unified framework for IDD statistics. This report briefly reviews past IDD prevalence and health surveillance work, describes the current national surveillance topography and outlines the likelihood that crucial national IDD data will fail to be collected unless action is taken. Finally, suggestions are made for areas to be measured in prevalence studies (learning, independent living skills, and age of onset) and a shorter set of constructs that could help identify IDD for health surveillance research (communication, self-direction, and expected duration). Methodological considerations to facilitate the swift movement to draft, test, and deploy items in national surveys to meet the need for national health surveillance of people with IDD are also reviewed.

Directions for future actives are offered:

1. AIDD/ACL and its partners intend to work with the research staff at the NCHS' CCQDER to construct and cognitively test survey questions that are valid, reliable, and appropriate to identify adults and children with IDD, including those from racially and ethnically diverse backgrounds. These questions are intended for future use in the NHIS and other surveys to identify people with IDD.
2. Once updated and benchmarked prevalence estimates are complete, the workgroup recognizes the value of regular prevalence survey iterations to guide future fiscal projections, policy development, and program planning. The workgroup recognizes that as statutes are changed, domains may need to be updated.
3. Continued collaboration across federal agencies and stakeholder groups will support broader implementation of health surveillance practices in national data collection systems that allow for better identification and prevalence estimates of IDD.

4. The representativeness of national surveillance systems will improve if they consistently include people in the U.S. territories.

With commitment and collaboration across federal, state, public, and private partners, adults with IDD will become visible in health surveillance data so that their services, support, and other needs can be understood and addressed across public and private sectors.

It always seems impossible until it is done.

-Nelson Mandela

VI. References

American Community Survey (ACS). (2017). Washington, DC: U.S. Census Bureau. Available at https://www.census.gov/programs-surveys/acs/

Americans With Disabilities Act of 1990, 42 U.S.C.A. 12101 *et seq.*

Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators. (2014). Prevalence of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report: Surveillance Summaries*, *63*(2), 1-21.

Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., … Dowling, N. F. (2018). Prevalence of autism spectrum disorder among children aged 8 years — Autism and developmental disabilities monitoring network, 11 Sites, United States, 2014. *MMWR Surveillance Summaries, 67*(6), 1–23. http://doi.org/10.15585/mmwr.ss6706a1.

Balogh, R. (2017). *Use of administrative data to address health and health service needs of Canadians with intellectual and developmental disabilities*. Presentation at the Data Needs to Inform Program Planning and Policies on Health of People with Intellectual and Developmental Disabilities. Washington DC: Administration on Intellectual and Developmental Disabilities, November 3, 2017.

Bersani, H., & Lyman, L. (2009). Governmental policies and programs for people with disabilities. In C. E. Drum, G. L. Krahn, & H. Bersani (Eds.), *Disability and public health* (pp. 79-104). Washington, DC: American Public Health Association and American Association on Intellectual and Developmental Disabilities.

Blumberg, S.J. (August 2012). Trends in the prevalence of developmental disabilities in US children, 1997-2008. Presented at the National Conference for Health Statistics, Washington, DC. Available at: https://www.cdc.gov/nchs/ppt/nchs2012/ss-22_blumberg.pdf; [Accessed 7/30/18].

Bonardi, A., Krahn, G., Morris, A., and the National Workgroup on State and Local Administrative Data on Intellectual and Developmental Disabilities. (2019). Enriching our Knowledge: State and Local Data to Inform Health Surveillance of the Population with Intellectual and Developmental Disabilities." Technical report to the Administration on Intellectual and Developmental Disabilities, August 2019.

Bonardi, A., Lauer, E., Mitra, M., Bershadsky, J., Taub, S., Noblett, C. (2011). Expanding surveillance of adults with intellectual disability in the US. Center for Developmental Disabilities Evaluation and Research (CDDER). E.K Shriver Center, University of Massachusetts Medical School. Available at: http://www.umassmed.edu/Content.aspx?id=157548&linkidentifier=id&itemid=157548; [Accessed 9/15/2017].

Bourke, J., de Klerk, N, Smith, T., & Leonard, H. (2016) Population-based prevalence of intellectual disability and autism spectrum disorders in Western Australia. *Medicine.* 95(21), e3737. Doi:10.1097/MD.0000000000003737

Boyle, C. A., Boulet, S., Schieve, L. A., Cohen, R. A., Blumberg, S. J., Yeargin-Allsopp, M., ... & Kogan, M. D. (2011). Trends in the prevalence of developmental disabilities in US children, 1997–2008. *Pediatrics*, *127*(6), 1034-1042. http://dx.doi.org/10.1542/peds.2010-2989

Braun, K. V. N., Christensen, D., Doernberg, N., Schieve, L., Rice, C., Wiggins, L., ... & Yeargin-Allsopp, M. (2015). Trends in the prevalence of autism spectrum disorder, cerebral palsy, hearing loss, intellectual disability, and vision impairment, metropolitan Atlanta, 1991–2010. *PloS one*, *10*(4), e0124120.Published: April 29, 2015 https://doi.org/10.1371/journal.pone.0124120

Braddock, D., Hemp, R., Tanis, E., Wu, J., Haffer, L. (2017). The state of the states in developmental disabilities (11th Edition). Washington, DC: American Association on Intellectual and Developmental Disabilities.

Braddock, D.L., Parish, S. (2001) An institutional history of disability. In G.L. Albrecht, K.D. Seelman, M. Bury (Eds.) *Handbook of disability studies*, Thousand Oaks CA: Sage Publications, pp 11-68.

Burke, M. M., & Fujiura, G. T. (2013). Using the Survey of Income and Program Participation to compare the physical health of non-caregivers to caregivers of individuals with intellectual and developmental disabilities. *International Review of Research in Developmental Disabilities, 45*, 257-280.

Centers for Medicare and Medicaid Services: http://www.cms.gov

Centers for Medicare and Medicaid Services. (n.d.). CAHPS Home and Community Based Services Survey. Retrieved from Medicaid.gov Centers for Medicare and Medicaid Services: https://www.medicaid.gov/medicaid/quality-of-care/performance-measurement/cahps-hcbs-survey/index.html

CESSI. *Federal Statutory Definitions of Disability. Technical report to the Interagency Committee on Disability Research.* Previously available at http://www.icdr.us/ and cited in Bersani H and Lyman L. (2009) Governmental policies and programs for people with disabilities. In C.E. Drum, G.L. Krahn and H. Bersani (Eds). *Disability and public health*, (pp. 79-104). Washington, DC: American Public Health Association and American Association on Intellectual and Developmental Disabilities.

Civil Rights Act of 1964, U.S. Public Law 88-352, 241 *et seq.*

Claes, C., Vandevelde, 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.

Cohen, J., Solomon, T., Joe, J., Haring, R., Randall, L, DeRoins, D. Manuel, M., Farkas, J. & Villavicencio, J. (2012). *Native American Developmental Disabilities Needs Assessment.* Silver Spring: Association of University Centers on Disabilities. Available at http://sonoranucedd.fcm.arizona.edu/sites/default/files/publication/native_am_needs_assmt_sm.pdf

Current Population Survey (CPS). (n.d.). Retrieved from United States Census Bureau: https://www.census.gov/programs-surveys/cps.html

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

de Graaf, G., Buckley, F., & Skotko, B. G. (2017). Estimation of the number of people with Down syndrome in the United States. *Genetics in Medicine, 19*(4), 439.

Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 US.C.A. 15001 et. seq.

Dixon-Ibarra, A., Horner-Johnson, W. (2014). Disability status as an antecedent to chronic conditions: National Health Interview Survey, 2006-2012. *Preventing Chronic Disease*, 11:E15.

Doljanac, R., Larson, S., & Lakin, C. (2004). Gender, Age, and Disability Differences in Functional Limitations for Non-Institutionalized Adults in the NHIS-D. *DD Data Brief, 6*(1). Minneapolis: University of Minnesota, Research and Training Center on Community Living.

ED*Facts* Data Warehouse (2017) *IDEA Part B Child Count and Educational Environments Collection,* 2016-2017. Data extracted as of July 12, 2017 from file specifications 002 and 089. Washington, DC: U.S. Department of Education.

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.medicaid.gov/medicaid/ltss/reports-and-evaluations/index.html.

Fast Facts: Students with Disabilities. (n.d.). Retrieved from IES NCES National Center for Education Statistics: https://nces.ed.gov/fastfacts/display.asp?id=64

Fish, J. M. (Ed.). (2002). *Race and intelligence: Separating science from myth*. London and Nahwah, NJ: Erlbaum.

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.

Fujiura, G. T., Li, H., & Magaña, S. (2018). Health services use and costs for Americans with intellectual and developmental disabilities: A national analysis. *Intellectual and Developmental Disabilities*, *56*(2), 101-118.

Fujiura, G.T. & Taylor, S.J. (2003). Continuum of intellectual disability: Demographic evidence for the "Forgotten Generation". *Mental Retardation, 41*, 420–429.

Fujiura, G. T., & Yamaki, K. (1997). Analysis of ethnic variations in developmental disability prevalence and household economic status. *Mental Retardation*, *35*(4), 286-294.

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 Suppl 3), S3-8. http://dx.doi.org/10.1097/MLR.0000000000000201

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

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, MD: Brookes Publishing.

Goode, T., & Maloof, P. (2010). End of life through a cultural lens. In S.L. Friedman and D.T. Helm (Eds.) *End of life care for children and adults with intellectual and developmental*

disabilities (pp. 147-159). Washington, DC: American Association on Intellectual and Developmental Disabilities.

Health and Retirement Study. (2016). Ann Arbor, MI: University of Michigan. Available at: https://hrs.isr.umich.edu/documentation

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

Hendershot, G., Larson, S., Lakin, C., & Doljanac R. (2005). DD Data Brief: *Problems in defining mental retardation and developmental disability: Using the National Health Interview Survey*. 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

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*, S40-S50. doi: 10.1097/MLR.0000000000000193

Horner-Johnson, W, Dobbertin K, Beilstein-Wedel, E. (2015). Disparities in dental care associated with disability and race and ethnicity. *Journal of the American Dental Association, 146*(6), p 366-374.

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.

Iezzoni, L.I., & Freedman, V.A. (2008). Turning the disability tide: The importance of definitions. *Journal of the American Medical Association, 299*(3):332–334. doi:10.1001/jama.299.3.332

Larson, S.A., Doljanac, R., & Lakin, K.C. (2005). United States living arrangements of persons with intellectual and/or developmental disabilities in 1995. *Journal of Intellectual and Developmental Disability, 30* (4), 248-251 https://risp.umn.edu/sites/risp.umn.edu/files/2018-06/risp2016-residence-type.pdf.

Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2017). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2015*. Research and Training Center on Community Living , University of Minnesota

Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2018). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2016.* Research and Training Center on Community Living , University of Minnesota n. Available at: https://risp.umn.edu/archive

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* (1). Available at https://www.ssa.gov/policy/docs/ssb/v77n1/v77n1p17.html

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. In *BMC public health* (Vol. 11, No. 4, p. S4). BioMed Central.

Maenner, M.J., Blumberg, S.J., Kogan, M.D., Christensen, D., Yeargin-Allsopp, M., & Schieve, L.A. (2016). Prevalence of cerebral palsy and intellectual disability among children identified in two U.S. National Surveys, 2011-2013. *Annals of Epidemiology*, *26*(3), 222-226. doi.org/10.1016/j.annepidem.2016.01.001.

Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. (2011). Prevalence of intellectual disability: A meta-analysis of population-based studies. *Research in Developmental Disabilities, 32*(2), 419-436.

McKenzie, K., Milton, M., Smith, G., & Ouellette-Kuntz, H. (2016). Systematic review of the prevalence and incidence of intellectual disabilities: current trends and issues. *Current Developmental Disorders Reports*, *3*(2), 104-115.

Mont, D. (2007). Measuring disability prevalence (English). *SP discussion paper; no. 706*. Washington, DC: World Bank. Retrieved from http://documents.worldbank.org/curated/en/578731468323969519/Measuring-disability-prevalence

Mumbardo-Adam, C., Guardia-Olmos, J., Adam-Alcocer, A.L., Carbo-Carrete, M., Balcells-Balcells, A., Gine, C., & Shogren, K.A. (2017). Self-determination, intellectual disability, and context: A meta-analytic study. *Intellectual and Developmental Disabilities*, 55(5), 303-314.

National Center for Education Statistics. Fast Facts. Available at https://nces.ed.gov/fastfacts/display.asp?id=64. Accessed 6.28.2018.

National Center for Education Statistics (2017) *National Elementary and Secondary Enrollment Projection Model, 1972 through 2026; Enrollment in Degree-Granting Institutions Projection Model, 2000 through 2026; Elementary and Secondary Teacher Projection Model, 1973 through 2026; and unpublished projections and estimates*. Washington DC: U.S. Department of Education.

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

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

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.

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

Newman, L., Wagner, M., Knokey, A.-M., Marder, C., Nagle, K., Shaver, D., Wei, X., with Cameto, R., Contreras, E., Ferguson, K., Greene, S., and Schwarting, M. (2011). T*he post-high school outcomes of young adults with disabilities up to 8 years after high school. A report from the National Longitudinal Transition Study-2* (NLTS2) (NCSER 2011-3005). Menlo Park, CA: SRI International.

Ohio Medicaid Assessment Survey (OMAS). (2017). Columbus, OH: Ohio Department of Medicaid. Available at http://grc.osu.edu/OMAS

Olmstead v. L.C., 527 U.S. 581 (1999)

Olmstead: Community Integration for Everyone. (n.d.). Retrieved from ADA.gov United States Department of Justice Civil Rights Division Information and Technical Assistance on the Americans with Disabilities Act: https://www.ada.gov/olmstead/olmstead_about.htm

OMH U.S. Department of Health and Human Services Office of Minority Health. (n.d.). Retrieved from HHS.gov OMH U.S. Department of Health and Human Services Office of Minority Health: https://minorityhealth.hhs.gov/

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. doi 10.1007/s40615-015-0140-9.

OSERS Office of Special Education and Rehabilitative Services. (n.d.). Retrieved from U.S. Department of Education: https://www2.ed.gov/about/offices/list/osers/programs.html

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*, S51-S63.

Pope, A. M., & Tarlov, A. R. (Eds.). (1991). *Disability in America: Toward a national agenda for prevention*. National Academies Press.

Rosa's Law of 2010, 42. U.S.C.A sec 1400

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.

State of the States in Intellectual and Developmental Disabilities. (n.d.). Retrieved from The State of the States in Intellectual and Developmental Disabilities: www.stateofthestates.org

Survey of Income and Program Participation. (n.d.). Retrieved from United States Census Bureau: https://www.census.gov/sipp/

Survey of Income and Program Participation (SIPP). (2014). Washington, DC: U.S. Census Bureau. Available at https://www.census.gov/programs-surveys/sipp/tech-documentation/questionnaires.html

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.ccsg.isr.umich.edu/

Tassé, M.,J., Schalock, R.L., Balboni, G., Bersani, H., Borthwick-Duffy, S,A., Spreat, S., Thissen, D., Widaman, K.F., Zhang, D. (2017). *Diagnostic Adaptive Behavior Scale User's Manual.* Washington, DC: American Association on Intellectual and Developmental Disabilities.

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

United States Census Bureau. (n.d.). United States Census Bureau. Retrieved from American Community Survey (ACS) Why We Ask: Disability https://www2.census.gov/programs-surveys/acs/about/qbyqfact/2016/Disability.pdf.

US Census Bureau (n.d.) How disability data are collected from The American Community Survey. Available at: https://www.census.gov/topics/health/disability/guidance/data-collection-acs.html. [Accessed 7/5/2018].

U.S. Department of Health and Human Services. (2002). Closing the gap: A national blueprint to improve the health of persons with mental retardation. In *Report of the Surgeon General's Conference on Health Disparities and Mental Retardation. Washington (DC): U.S. Department of Health and Human Services*.

U.S. Department of Health and Human Services, Office of Minority Health. (2013, 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.

Van Naarden Braun, N., Christensen, D., Doernberg, N., Schieve, L., Rice, C., Wiggins, L., ... & Yeargin-Allsopp, M. (2015). Trends in the prevalence of autism spectrum disorder, cerebral palsy, hearing loss, intellectual disability, and vision impairment, metropolitan Atlanta, 1991–2010. *PLOS one*, *10*(4), e0124120.

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. (2011). *Health topics: Disabilities.* Retrieved from http://www.who.int/topics/disabilities/en/

World Health Organization (2001). *International Classification of Functioning, Disability and Health (ICF).* Retrieved from http://www.who.int/classifications/icf/en/

World Health Organization. (1998). Primary prevention of mental, neurological and psychosocial disorders. Retrieved from https://apps.who.int/iris/bitstream/handle/10665/42043/924154516X_eng.pdf.

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

Zablotsky B., Black L.I., Maenner M.J., Schieve L.A., Blumberg S.J. (2015). Estimated prevalence of autism and other developmental disabilities following questionnaire changes in the 2014 National Health Interview Survey. *National Health Statistics Reports, 87*, 1-20.

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

Appendices

Appendix A: Comparing ID (AAIDD) and DD (DD Act)

Standard	Intellectual Disability (AAIDD)	Developmental Disabilities (DD Act of 2000)
Age of onset	Before age 18	Before age 22
Cause	Based on biomedical, social, behavioral, and educational risk factors	Attributable to mental or physical impairments
Severity	2 standard deviations below the mean on standardized tests	Severe, resulting in substantial functional limitations in three areas
Duration	Lifelong	Continues indefinitely; Of lifelong or extended duration
Supports needed	An important purpose of describing limitations is to develop a profile of needed supports. With appropriate personalized supports over a sustained period, the life function of the person with ID generally will improve	Requires a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are individually planned and coordinated
Practice Issues	State agencies may establish eligibility criteria for services that do not perfectly align with the AAIDD definition of ID. For example, a state may expand their service recipient pool to include those with "related conditions" such as autism spectrum disorder, cerebral palsy, spina bifida, epilepsy, and hydrocephalus whose needs are similar to those of a person with ID	Children ages 9 years or younger who have a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria … if the individual, without services and supports, has a high probability of meeting those criteria later in life.
Domains	**Substantial Limitations in Cognitive and Adaptive behavior**	**Substantial Functional Limitations**
Cognitive	Intellectual functioning, or intelligence, is a general mental ability that includes reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas, learning quickly, and learning from experience	Learning

Adaptive behavior (the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives)	Conceptual skills—language and literacy; time, and number concepts;	Learning
Adaptive behavior (the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives)	Social skills—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.	Receptive and expressive communication
Adaptive behavior (the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives)	Practical skills—activities of daily living (personal care), occupational skills, healthcare, travel/ transportation, schedules/ routines, safety, use of money, use of the telephone.	Capacity for independent living, self-care, economic self-sufficiency, mobility, and self-direction

Appendix B. Items in population-based surveys used to identify ID or DD

The Developmental Disabilities Act of 2000 defines developmental disabilities (DD) based on the age at onset of disability, severity of disability, expected duration of disability, and the presence of substantial functional limitations in at least three of seven domains. The seven domains include self-care (also known as activities of daily living[ADL]), independent living (also known as instrumental activities of daily living [IADL]), communication, economic self-sufficiency, mobility, learning, and self-direction.

The following tables list items from population-based surveys that assess the elements of the Developmental Disabilities Act definition of DD and the American Association on Intellectual and Developmental Disabilities (AAIDD) definition of intellectual disability (ID):

- Table B1 2016 National Health Interview Survey (NHIS) - adults
- Table B2 1994-1995 National Health Interview Survey - Disability Survey (NHIS-D) adults
- Table B3 2008-2013 Survey of Income and Program Participation (SIPP) adults
- Table B4 2008-2013 SIPP children
- Table B5 World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0)

The 2016 NHIS survey included items covering five of the seven functional limitations described in the DD Act definition of DD. It did not include items on limitations in self-direction or learning, nor did it ask age at onset of disability or if the limitation was expected to continue indefinitely. It did ask whether ID, Down syndrome, cerebral palsy, epilepsy, spina bifida, or hydrocephalus was the primary cause of reported limitation.

National Health Interview Survey (2016)

Table B1. 2016 NHIS Items used to screen adults for intellectual or developmental disabilities.

Survey	Subscale	Item Stem	Limitation Type
NHIS	AFD	Difficulty with self-care	self-care
NHIS	Family	Need help with personal care	self-care
NHIS	Family	Need help with bathing/showering	self-care
NHIS	Family	Need help dressing	self-care
NHIS	Family	Need help eating	self-care
NHIS	Family	Need help in/out of bed or chairs	self-care
NHIS	Family	Need help using toilet	self-care
NHIS	Family	Need help with routine needs	self-care
NHIS	AFD	Difficulty communicating in usual language	communication
NHIS	Interviewer	Did the person require a proxy respondent because of disability related limitations	communication
NHIS	Family	Condition now keeps from work	economic
NHIS	Family	Limited in kind/amount of work	economic
NHIS	Sample Adult	Difficulty w/ social activities	social participation
NHIS	Sample Adult	Difficulty w/ leisure activities	social participation
NHIS	Sample Adult	Difficulty w/ shopping	Independent living
NHIS	AFD	Difficulty walking or climbing steps	Mobility
NHIS	AFD	Someone's assistance with getting around	Mobility
NHIS	Sample Adult	Difficulty walking quarter mile	Mobility
NHIS	Sample Adult	Difficulty 10 steps	Mobility
NHIS	Sample Adult	Difficulty standing two hours	Mobility
NHIS	Family	Need help to get around house	Mobility
NHIS	Family	Have difficulty walking without equipment	Mobility

National Health Interview Survey-Disability Survey (1994/95)

Table B2. 1994-95 NHIS-D items used to identify adults with IDD.

Survey	Subscale	Item Stem	Key Element
NHIS-D		Person currently has mental retardation	Diagnosis of ID
NHIS-D		Mental retardation was indicated as the cause of age-specific general activity limitations. General activity limitations included limitations in play for children ages 5 and younger, limitations in school activities for children ages 5 to 17, limitations in work for adults ages 18 to 69, and overall limitations in activities for people of all ages.	Diagnosis of ID
NHIS-D		Mental retardation was identified as the primary cause of limitations in communication, getting along with others, activities of daily living, instrumental activities of daily living, and other functional limitations; or if mental retardation was the ICD code listed as the reason the person had a doctor's visit, a physician consultation regarding communication, or as the reason for receiving occupational therapy.	Diagnosis of ID
NHIS-D		Has autism, cerebral palsy, Down syndrome, spina bifida, or hydrocephalus. Or, Does condition file list a related condition as the cause of either age-specific general activity limitations in the Core Survey, as the cause of specific activity limitations (e.g., communicating, getting along with others) or as the reason for receiving various services (e.g., occupational or physical therapy) in the Phase 1 Disability Supplement AND a learning disability AND significant functional learning limitations.	Diagnosis of conditions associated with ID

NHIS-D		Has DD based on DD Act definition of three or more significant functional limitations occurring before age 22 expected to continue indefinitely.	Has DD
NHIS-D		A person 18 years or older "has serious difficulty" or "cannot use" the telephone.	Communication/Expressive or Receptive Language
NHIS-D		A person 5 years or older "has serious difficulty communicating so the family can understand" or "has serious difficulty understanding others when they talk or ask questions."	Communication/Expressive or Receptive Language
NHIS-D		Difficulty communicating with people outside of the family.	Communication/Expressive or Receptive Language
NHIS-D		Difficulty communicating in usual language.	Communication/Expressive or Receptive Language
NHIS-D		Has dx of mental retardation or had serious difficulty learning how to do things that most people their age are able to learn AND does not have Alzheimer's or another senility disorder AND less than 2 years post-secondary education completed.	Learning
NHIS-D		Has a learning disability.	Learning
NHIS-D		A person 5 years or older "has a lot of difficulty" or "is unable" to dress, eat, bathe, get in and out of bed or chairs, use the toilet, or get around the house.	Self-care
NHIS-D		A person 18 years or older "requires help or supervision" or "has a lot of difficulty with" or "is unable" to prepare meals, shop for personal items or medicine, manage his or her money, do light work around the house (such as doing dishes, straightening up, light cleaning or taking out the trash) or do heavy work around the house.	Independent Living
NHIS-D		Activities in last two weeks: meet with friends or neighbors, talk on phone with friends or neighbors, meet with relatives or family, talk on phone with relatives or family, attend religious	Social participation

		services, attend events, eat at a restaurant.	
NHIS-D		Go out every day, did not leave home at all in last two weeks, satisfied with frequency of social activities.	Social participation
NHIS-D		A person 18 years or older "has participated in" or is "on the waiting list" for a sheltered workshop, transitional work training, supported employment or a day activity center; or "is unable to work" because of a mental or emotional problem.	Economic Self-Sufficiency
NHIS-D		A person 18 years or older "has never been able to work" or "is currently unable to work because of a mental or emotional problem" or "is limited in kind or amount of work" due to a limitation; or "has trouble finding or keeping a job or doing job tasks because of a mental or emotional problem."	Economic Self-Sufficiency
NHIS-D		A person 18 years or older has or needs a "case manager to coordinate personal care, social or medical services" or "has a court appointed guardian" during the last 12 months.	Self-direction
NHIS-D		A person 5 years or older, because of a physical, mental or emotional problem, "needs to be reminded or have someone close by" for dressing, eating, bathing, toileting, or transferring.	Self-direction
NHIS-D		A person 5 years or older "has difficulty" or "is unable" to walk up 10 steps, walk three city blocks, or getting in or out of bed or chairs.	Mobility
NHIS-D		Difficulty walking or climbing steps	Mobility
NHIS-D		Equipment/help to get around	Mobility

NHIS-D		Uses special equipment	Mobility
NHIS-D		Have difficulty walking without equipment	Mobility
NHIS-D		Use cane	Mobility
NHIS-D		Use walker	Mobility
NHIS-D		Use crutches	Mobility
NHIS-D		Use wheelchair scooter	Mobility
NHIS-D		Artificial limb	Mobility
NHIS-D		Someone's assistance with getting around house	Mobility
NHIS-D		Other equipment	Mobility
NHIS-D		Difficulty walking 100 yards without aids	Mobility
NHIS-D		Difficulty walking 1/3 mile without aids	Mobility
NHIS-D		difficulty walking quarter mile	Mobility
NHIS-D		Difficulty up/down 12 steps	Mobility
NHIS-D		Difficulty up/down 10 steps	Mobility

Survey of Income and Program Participation (2008-2013)

Table B3. 2008-2013 SIPP items used to identify adults with IDD

Survey	Subscale	Item Stem	Key Element
SIPP	IDD Screens: Adult	*I have recorded that [fill TEMPNAME] health is fair or poor. Which condition or conditions cause these difficulties?* (Age 15+ years only) (Item ADQ33) [SHOW CONDTION FLASHCARD – 30 conditions including cerebral palsy, epilepsy, learning disability, mental retardation]	Conditions associated with DD
SIPP	IDD Screens: Adult	*Any Others?* [UP TO THREE}	Conditions associated with DD
SIPP	IDD Screens: Adult	*Which of the conditions that you mentioned do you consider to be the main reason for [fill PTEMPNAME] difficulties?* [FILL IN UP TO THREE CONDITIONS (Age 15+ years only- Item ADQ35)]	Conditions associated with DD
SIPP	IDD Screens: Adult	*Does [fill TEMPNAME] have* – [(Age 15+ years only) (Item ADQ39)] *(1) Yes (2) No* *a. A learning disability such as dyslexia?*	Conditions associated with DD
SIPP	IDD Screens: Adult	*b. Mental retardation?*	Conditions associated with DD: ID diagnosis
SIPP	IDD Screens: Adult	*c. A developmental disability such as autism or cerebral palsy?*	Conditions associated with DD
SIPP	IDD Screens: Adult	*d. Alzheimer's disease or any other serious problem with confusion or forgetfulness?*	Conditions that inform DD determination (rule out)
SIPP	IDD Screens: Adult	*e. Any other mental or emotional condition?*	Conditions associated with DD
SIPP	IDD Screens: Adult	*I have recorded that [fill TEMPNAME] [fill HAVHAS] a limitation in working [fill* *TEMPQ47]. Which condition or conditions cause this limitation?*	Economic self-sufficiency

Survey	Subscale	Item Stem	Key Element
		[SHOW CONDTION FLASHCARD– 30 conditions including cerebral palsy, epilepsy, learning disability, mental retardation] [(Age 16-72 years only) (Item ADQ47)]	
SIPP	IDD Screens: Adult	*Any Others?* [UP TO THREE] *Specify the exact "Other" condition that causes your work limitation.* [(Item ADQ47A) (Age 16-72 years only)]	Economic self-sufficiency
SIPP	IDD Screens: Adult	*Which of the conditions that you mentioned do you consider to be the main reason for [fill PTEMPNAME] limitation?* [FILL IN UP TO THREE CONDITIONS– 30 conditions including cerebral palsy, learning disability, mental retardation] [(Age 16-72 years only) (Item ADQ48)]	Economic self-sufficiency
SIPP	IDD Screens: Adult	*For how long [fill HAVHAS] [fill TEMPNAME] needed help of another person?* *(1) Less than 6 months (2) 6 to 11 months (3) 1 to 2 years (4) 3 to 5 years (5) More than 5 years* [(Age 15+ years only) (Item ADQ29)]	Age of Onset
SIPP	IDD Screens: Adult	*When did [CONDITION]first begin to bother [fill TEMPNAME]?* [ENTER 4 DIGIT YEAR (Item ADQ36)]	Age of Onset
SIPP	IDD Screens: Adult	*Is this condition expected to last for at least 12 more months?* *(1) Yes (2) No* [(Items ADQ38, ADQ39, ADQ47,)]	Duration

Table B4. 2008-2013 SIPP items used to identify children with IDD

Survey	Subscale	Item Stem	Element
SIPP	Child IDD Screen	*Does ... have a serious physical or mental condition or a developmental delay that limits ordinary activities?* *(1) Yes (2) No* [(Age less than 6 years only) (Item CDQ1A)]	Limitation
SIPP	Child IDD Screen	*Does ... have a learning disability* *(1) Yes (2) No* [(Age >= 6 and < 15 years only) (Item CDQ6.1)]	Condition association with DD
SIPP	Child IDD Screen	*Does ... have mental retardation?* *(1) Yes (2) No* [(Age >= 6 and < 15 years only) (Item CDQ6.2)]	ID diagnosis
SIPP	Child IDD Screen	*Does ... have a developmental disability such as autism or cerebral palsy?* *(1) Yes (2) No* [(Age >= 6 and < 15 years only) (Item CDQ6.3)]	Condition association with DD
SIPP	Child IDD Screen	*Does ... have any other developmental condition for which he or she has received therapy or diagnostic services?* *(1) Yes (2) No* [(Age >= 6 and < 15 years only) (Item CDQ6.5)]	Diagnosis or treatment for condition association with DD
SIPP	Child IDD Screen	*I have recorded that ... has difficulty with certain activities. Which condition or conditions cause this difficulty?* [SHOW CHILDHOOD CONDITIONS FLASHCARD – 23 conditions including cerebral palsy, epilepsy, learning disability, mental retardation] [Age >= 6 and < 15 years only) (Item CDQ29.1)]	Condition association with DD
SIPP	Child IDD Screen	*Any Others?* [UP TO THREE]	Condition association with DD

World Health Organization Disability Assessment Schedule (WHODAS 2.0)

Table B5. WHODAS 2.0 items describing DD Act functional limitations in adults with DD

DD Act Domain	Question: In the last 30 days how much difficulty did you have in:
Learning	• Analyzing and finding solutions to problems in everyday life
	• Learning a new task, for example, learning how to get to a new place
Communication	• Generally understanding what people say
	• Starting and maintaining a conversation
Independent Living	• Staying by yourself for a few days
	• Doing the most important household tasks well
	• Getting your household work done as quickly as needed
Other Domains	**Question: How much of a problem do you have:**
Social participation	• Dealing with people you do not know
	• Maintaining a friendship
	• Getting along with people who are close to you
	• Making new friends
	• Joining in community activities
Recreation	• Doing things for relaxation or pleasure by yourself

Table adapted from Ustuen et al, (2010)