Intellectual and Developmental Disabilities

Through the Looking Glass: Health of People with Intellectual and Developmental Disabilities

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Abstract:	Population level data on health of people with intellectual and developmental disabilities (IDD) are sorely needed to identify their health status, health disparities, and health needs. Key considerations to inform programs and policies address prevalence, problem identification, and progress assessment. Recent advances in health data about people with disabilities generally identify strategies for improving health data for people with IDD, including importance of a standardized operational definition and survey identifiers of IDD. Past and current actions by federal agencies' to improve health data for health equity are summarized. Emerging developments in IDD health data are identified, including increasing use of self-report, data linking and harmonizing, intersectionality and recognition of ableism.

Through the Looking Glass: A Data Lens on Health of People with Intellectual and Developmental Disabilities

Running Title: Health Data for People with IDD

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Health Data for People with IDD

We live in an era of data—data-driven decision-making, data-informed policy, Big Data algorithms that steer programs. But until very recently, there was a dearth of health data on people with disabilities, and that paucity continues for people with intellectual and developmental disabilities (IDD). The conundrum that disability advocates face is that one can't convince others of the importance of gathering good data, without good data to make the case.

Recently, however, growing attention to data and the lack thereof on the health and wellbeing of people with disabilities, including IDD, is generating a swirl of discussion on definitions, data collection strategies and priorities, and conceptual frameworks. The current paper reflects a synthesis of the perspectives of the authors who have been working for the past two decades to improve data on the health and health disparities of people with disabilities, especially IDD. Our shared belief is that it is critical to make people with IDD visible in data that identifies their health status, needs, and care utilization. The purpose of this paper is to aid readers to become better consumers of health data for people with IDD, particularly data that influence policy and programs at a national and state level.

The advances in health data described in this paper did not "just happen." They resulted because of the dedicated and persistent work of many heroes pushing for data improvement for a population that many would seemingly rather ignore. The title is a nod to Lewis Carroll's Alice in Wonderland and Through the Looking Glass. We see strong parallels between Alice's fantastical journey and the historical journey of health data for people with IDD. The paper provides several framing tools to guide the journey into data, examines advances and challenges, presents a history of how federal agencies have been improving health data, and summarizes emerging developments in IDD health data.

To illustrate, consider the following history. In 2009 and 2010, the Department of Health and Human Services (HHS) was developing an action plan to reduce racial and ethnic health disparities. For some time, people with disabilities were included in that action plan. But, when the decision was made to focus exclusively on race and ethnicity, a tentative promise was made that disabilities would get its own action plan. With no evident movement towards such a disability plan, disability advocates pushed for a meeting with the Assistant Secretary for Health. They had received warning that they would hear: "There aren't enough data to support an action plan"—a familiar message in the past. When the HHS staff opened the door to the meeting, the advocates walked in with a tall stack of binders, pre-emptively saying "Here's the data!" A result of the meeting was agreement to develop a disability action plan. Several federal staff, including the first author, worked across 11 agencies for months in 2011 and 2012 to develop a justification report and a series of actions for the plan, pulling together data from multiple sources. When the plan was almost ready for clearance, it once again encountered resistance, and it became clear that the plan was not going to move forward in a timely way. Rather than abandon it, the three writers determined to publish the data synthesis as a journal article. That paper (Krahn, Walker, Correa de Araujo, 2015) was published in early 2015 and it accomplished its intention—it became a seminal paper that others could reference as documenting that people with disabilities are a health disparity population. The Centers for Medicare and Medicaid Services declared disability as a health disparity population later in 2015, and then the National Institutes of Health (NIH) became the focus for advancing attention to disabilities. Fast forward to 2022 when NIH tasked a work group to consider whether disability should be considered a health disparity population. The workgroup report in 2023

recommended against considering disability a health disparity population for familiar reasons—lack of data and lack of a common definition. Once again, disability advocates took on the challenge. NIH did not follow the workgroup recommendation and, instead, determined disability to be a health disparity population in fall of 2023. What that meant is funding started to flow; ironically, funding to help create better data.

Framing Tools for Exploring Disability Data

"It's no use going back to yesterday, I was a different person then," Alice tells the Mock Turtle.

The Power of Data

The power of data is that it changes people's views. Once we know, we cannot "unknow." Once the magnitude and meaning of health disparities of people with IDD have been documented and communicated, they demand action. The corollary is that we forget how much we didn't know in the past, and that tomorrow others will view the situation differently from our current perspective. This work is a continuous process of framing and reframing. One perspective is to think about data as anchors of reality; alternatively, data can be seen as ways by which we construct our understanding of reality.

Levels of Data

In brief, health data can be considered at three levels. At an individual and clinical level, practitioners conduct in-depth assessment of an individual person's strengths and needs. An interdisciplinary diagnostic team synthesizes data from multiple perspectives to develop an understanding of how this individual child, youth or adult processes information, responds to their environment, and functions in school, work, relationships, and in the community.

In a research context, researchers typically collect data on samples of people who derived from larger groups. Groups may be defined by diagnoses (e.g., Down syndrome), demographic characteristics (e.g., age, race, sex) or environmental situations (e.g., living in group homes). Researchers often look for differences in averages across the groups. These groups may be clinically based or recruited from the general population, but with less attention to random selection.

For populations, the intent is that the data are representative of all members of a specified population—whether that is all people with IDD in a country or from a defined group. For example, health plans often refer to their enrollees as their plans' populations. For population data, focus is on how the sample was derived to achieve as random a selection as possible to avoid and manage selection biases. Surveys typically ask fewer question on a specific topic than clinical or research-based data. This paper focuses on population data because these are the data typically used to influence programs and policies.

Conceptual Paradoxes

In the spirit of Alice and the paradoxes she encountered, we note two paradoxes with disability data. These paradoxes have seemingly been accepted because they have worked for some purposes in the past. However, they create challenges in other ways for moving forward.

The first paradox is that, while we understand many conditions to be on a continuum or spectrum, we treat these conditions as dichotomous. In a clinical context this translates to "Does this person qualify for this diagnosis?"; in a program eligibility determination, it is "Does this person qualify for these services?"; and in epidemiological data "Does this person meet requirements to be counted as a case?" In each instance, we have created an operational

definition of the condition to be dichotomous, all the while knowing that we are including and excluding people based on an artificial dichotomy.

A second paradox for IDD data relates to prevalence of children's conditions versus adult conditions. There are typically much higher estimates of IDD among children than adults. A recent government report cited rates of 7% of IDD in children and 0.9% in adults (Dhopeshwarkar et al, 2022). This phenomenon of abrupt reduction in prevalence rates from childhood to adulthood has been termed the "transition cliff" (e.g., Emerson & Glover, 2012). Our definitions of IDD are so widely variable between children and adults that our estimates vary by a factor of eight! In contrast, prevalence of overall disability in children, adults and aging adults shows increment with age, children having much lower prevalence estimates, increasing in middle age related to injuries and other acquired disabilities, and substantially increasing in older adults due to chronic diseases and aging-related disabilities.

IDD vs Disability

In the US, there has been an historical tension between IDD and Big D (or all disability) regarding data. If there is a hierarchy among types of disability, then mental health and IDD seem to be at the bottom of that hierarchy. That makes more understandable the protective stance within the IDD community to advocate more narrowly for their needs. On the other hand, within the US, the targeted attention and funding to IDD achieved through the DD Act has generated some resentment by other disability groups who complain of not getting their fair share of resources. In addition, single diagnosis groups still yield considerable political power for funding, as witnessed by funding for autism and Down syndrome. More recently, it appears that this tension may be abating.

Key Data Indicators for Policy

When immersed in IDD data, it is easy to get confused, with many points of dispute and distraction. Like Alice in Wonderland watching for the White Rabbit, it is helpful to keep our eye on some basic data points. These questions generally underlie the interests of policy-makers and program planners.

- Prevalence—how many people are we talking about? Prevalence relates directly to our definition of IDD
- Problems—what are the health indicators to attend to? Importantly, where can we make a difference? What are the other indicators (like social factors) that we need to include?
- Progress—given existing policies and programs, is the situation improving? If not, why not, and should we continue funding these programs?

Always present are the politics of who may have interest in which issues, and who has most direct access to the ears of legislators and policy-makers.

Down the Rabbit Hole of Disability Data

Prevalence of Disability

Disability Surveillance Data in the Past Decades

Over the past several decades, IDD data has benefited from important advances in Big D data, both conceptually and in data collection. Following passage of the Americans with Disabilities Act in 1990, the lack of disability data became immediately apparent. That initiated joint planning across multiple federal agencies and the Robert Wood Johnson Foundation to develop and implement a national survey on disability using the National Health Interview

Survey (NHIS) platform. This resulted in the NHIS-D Supplement 1994/95, the most comprehensive health survey on persons with disability in the US. It has not been repeated and does not provide surveillance data, but the data from the NHIS-D 94/95 have yielded hundreds of informative studies in the ensuing decades.

Importantly, IDD data are firmly nested within Big D data. Most people with IDD are present in the Big D data; the problem is that they cannot be identified. Others who live in institutional settings are not included in many national surveys. With improvements in Big D identifiers in surveys, we can better parse out the data for the disability subpopulation, but not for IDD. Until we have better identifiers for people IDD, they will continue to be unidentifiable among the respondents and, therefore, their health status and health needs go unnoticed. They will continue to be invisible in the data and be denied the rights of health equity.

How surveillance systems work, in brief, is that a survey, like the NHIS, asks many questions relating to health of a nationally representative group of noninstitutionalized people. If we have good identifier questions on disability and on IDD embedded within the core questions of a survey, then we can identify those respondents, pull out their health data, and potentially compare them with other respondents who aren't identified with disability. This differs from a survey that is designed specifically for people with disabilities like the NHIS Disability supplement of 1994-95. The practice of embedding disability identifiers in general surveys allows: 1) good prevalence estimates of people with disability and with IDD; 2) ongoing data, year after year about their health status; and 3) comparison of health status of people with disabilities to health of people without disabilities.

These disability identifiers are critically important. Developing “standard questions to identify people with disabilities in data sets” was the first disability objective of Healthy People 2010, the framework for U.S. public health goals for the coming decade. When that objective was not met by 2010, it was carried forward into Healthy People 2020 and finally achieved through the Affordable Care Act (ACA) of 2010. To address health disparities, the ACA included Section 4302(a) that required data-collection standards for five demographic categories: race, ethnicity, sex, primary language, and disability status. In 2011, following a tight time-line of negotiations among relevant agencies, data collection standards were established by HHS to identify these categories of people. For disability status, it called for six questions to be used. Since then, that 6-question set has been incorporated increasingly in national surveys.

Prevalence is directly linked to this operational definition of disability for surveys. Drawn from the American Community Survey and known as the ACS-6, these questions ask about serious difficulty in hearing; seeing (even when wearing glasses), concentrating, remembering or making decisions, walking or climbing stairs; and difficulty dressing or bathing, and doing errands alone such as visiting a doctor’s office or shopping. Responses to the questions are “Yes” or “No.” The ACS-6 uses a functional definition and departs from a diagnostic approach.

Intellectual disability is intended to be picked up by the question: “Because of a physical, mental or emotional condition, do you have serious difficulty concentrating, remembering or making decisions?”. Unfortunately, that question also picks up mental health difficulties, traumatic brain injury, stroke, and dementia. This problem was recognized at the time of the question’s adoption but, without a better question with demonstrated utility in measuring intellectual disability, it was adopted, combining respondents across meaningful differences.

An alternative question set for identifying disabilities in surveys that is also based on functional limitations is the Washington Group Short Set (WGSS). These questions serve as an international standard for measuring disability, are used by other countries in their censuses, and used in the U.S. in the National Health Interview Survey. Similar to the ACS-6, these questions ask about vision, hearing, mobility, cognition, and self-care; they include a question on communication but not on independent activity. Responses are recorded on a four-point continuum of severity. The WGSS question on cognition, however, isn't better for identifying IDD than the ACS-6 question.

Difficulties in Estimating Prevalence of Disabilities

Overall prevalence estimates of people in the U.S. with disabilities vary widely from 9% to 27% (Mitra et al, 2022). This three-fold magnitude of discrepancy challenges the credibility of any estimates, as noted by the NIH. To understand these discrepant estimates, we consider the questions asked, the response options, the method of administration, and the response rates.

How Much Difference do the Questions Make? It's not often that data are available on two question sets used with the same respondents in the same survey, but it occurred in 2013. In the absence of national standards, around 2001 the CDC Disability group began to use two questions for disability identification on the Behavioral Risk Factor Surveillance System (BRFSS). Those questions were: 1) "Are you limited in any way in any activities because of physical, mental, or emotional problems?"; and 2) "Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?" In 2013, BRFSS transitioned from using this older 2-question set to the ACS-6 question set. The BRFSS is administered through telephone calls and, in the first two years of

using the ACS questions, the BRFSS did not include the Hearing question. This was based on the mistaken belief that people with hearing problems would not respond to a telephone survey. For the 5-question set it is limitations in seeing (even with glasses), walking or climbing stairs, concentrating/remembering/making decisions, dressing or bathing, and doing errands alone like visiting a doctor's office or shopping.

The overall findings showed remarkably similar prevalence rates (Stevens et al, 2016). The 2-question set estimated 21.6% of the overall population having a disability and the 5-question set 22.7%. However, in looking at who was identified by the two different question sets, there was a great deal of difference. In fact, there was only a 51% overlap across the question sets. Almost one-half of the people identified as having a disability on one question-set were not identified with the other. The older, two question set was more likely to be endorsed by older, male, white non-Hispanic respondents; while the 5-question set drew younger, more Hispanic respondents who reported poorer mental health. Importantly, people with the most significant limitations were believed to be identified consistently across both question-sets. The variability in being identified arose among people with less severe limitations. The questions make a big difference, especially for people with milder limitations.

How Much Difference Does the Modality of Collecting the Data Make? Without a similarly clean study to address modality, comparison across surveys conducted in the same year provide some insights. Mitra and colleagues (2022) compared results of several different surveys, all from 2019, and examined prevalence of disability. The Behavioral Risk Factors Surveillance System (BRFSS) is a telephone survey administered by states with a response rate of 31-64% across states in 2019. The American Community Survey (ACS) is part of the census

and uses mailings, followed by email contact for non-responders, followed by telephone calls, and finally in-person interviews to reach almost all its intended sample (95% in 2019). Importantly, both surveys use the same ACS-6 questions to identify disability.

Table 1 shows the findings across these two surveys for two different age groups—ages 18-65 and over 65 years The differences are striking. For working age adults, ages 18-65, the BRFSS identifies more than twice as many having a disability than the ACS with the same questions. These findings suggest that a telephone survey that only reaches about half of the intended sample appears biased towards identifying more people with disabilities than are counted when almost all of the intended sample is reached.

What Differences Do Response Options and Cut-points make? The NHIS administers the WGSS questions by in-person interviews, often considered the gold standard in health surveillance. These questions ask about function in very similar categories as the ACS-6. It typically uses the cut-point of "little" or "some difficulty" as meaning no disability and "a lot of difficulty" or "cannot do at all" as identifying disability status. Its response rate in 2019 was 61%. The NHIS data presents another large drop in estimated prevalence of disability (Table 1).

This difference likely stems from not counting people reporting "some difficulty." This illustrates the paradox of creating dichotomies when we know limitations are experienced on a continuum. A compromise might seem to be to change the cut-point and include "some difficulty" in disability identification. But the concern with that is it leads to high rates of "false positives." False positives are people who endorse the question with "some difficulty" but do not have functional limitations considered "disability" in a usual sense. For example, in response to the question about difficulty in remembering or concentrating, "some difficulty"

might be reported by a sleep-deprived new mother; or someone working in a very noisy and distracting environment. It appears that in measuring disability status, the questions, modality, response rate matters, and response options in degree of severity of limitation all matter.

Prevalence of Intellectual and Developmental Disabilities

Prevalence data for IDD in adults is in large part grounded in the definition for intellectual disability of the American Association on Intellectual and Developmental Disabilities (AAIDD) and for developmental disabilities by the Developmental Disabilities Act (DD Act). These are definitions essentially based on functioning and require a significant limitation or set of limitations to meet the operational criteria for ID and DD.

A systematic review by Anderson and colleagues (2019) identified 14 studies reporting prevalence of IDD in US children and adults across different data sources. Prevalence rates for adults based on NHIS-D 1994/95 were 0.79% using the DD Act definition (Larson, et al 2001) and 1.27% when milder limitations were also included (Fujiura, 2003). ID and DD do not fully overlap because the DD Act definition for DD is quite stringent, requiring significant limitations in at least three areas. If a person has significant limitations in learning but not in two other areas, that person will not be considered to have DD. That was the situation for 46% of people identified with ID in 1994/95 but not DD (Larson et al, 2001).

For children, however, estimates are much more variable. Some surveillance systems like the NHIS use parent report on diagnostic categories for developmental disabilities (such as cerebral palsy or autism) without regard for severity of the limitation. When high incidence conditions are included, such as learning disability or attention deficit disorder, the prevalence

estimates of developmental disorders reach 15.4% to 17.8% (Boyle, et al, 2011; Zablotsky et al, 2019). These differences are largely due to the level of severity and the conditions included.

The importance of counting people with milder IDD

Numerous advocates and researchers direct attention to the importance of considering people with milder IDD who may not qualify for the AIDD or DD Act definitions, but who are still in need of services and supports. These reminders about "the forgotten generation" and "invisible populations" have been heralded by The President's Committee (1999), Fujiura (2003), and most recently by Rosencrans and colleagues (2021). This "invisible" population includes people who are missing from data collection systems, or who may meet diagnostic criteria but are not currently served through the DD service systems or, for other reasons, are not readily identified by researchers. These are the people about whom we know the least concerning their health status and health needs.

Determining the Problem—What Health Indicators to Assess

Defining the problem requires focusing on those health indicators on which we need data. Health indicators are summary measures designed to describe particular elements of health or aspects of health systems. Used over time (see Table 1), indicators can indicate direction and speed of change. In public health and for IDD, attention has expanded from looking almost exclusively at the metrics of mortality and morbidity, to valuing quality of life. Attention expanded to examining the influences on health outcomes including indicators of healthy life behaviors and more recently to environmental factors and social factors. In a 2010 review of priority health indicators for the general population and persons with IDD (Krahn et al, 2010), social factors like discrimination and ableism were not yet an area of significant attention.

Available Resources for Health Indicators for People with IDD

National Core Indicators. The National Core Indicators (NCI-IDD) started in 1997 as a quality assurance tool and includes data from up to 48 states and the District of Columbia. NCI includes carer and self-reported data, and currently contains indicators on preventive health services, having a primary doctor, dental exams, vision screening, and overall health. Its major limitation for research and prevalence purposes is that it provides data only on people who receive DD services, estimated to be about 40% of all people with IDD (Larson et al, 2021).

Special Olympics Healthy Athletes System. Also starting in 1997, Special Olympics began collecting data from free health screenings in multiple disciplinary assessments offered to its athletes. The data comprise the Healthy Athletes System (HAS) with more than 1.1 million digitized screenings to date. Data are collected in the areas of medical history and physical examination, vision, hearing, oral health, prevention and nutrition, fitness, foot health, mental and emotional health, and developmental screening for young children. When used for research, it presents the limitation of the data being limited to Special Olympics participants, with little information on generalizability to the overall population of people with IDD.

ID in general surveillance. Innovative researchers have used other data sets by developing alternative approaches to identify respondents who likely experience IDD. Using Medical Expenditure Panel Survey data which are representative of the national population, Reichard and colleagues documented in 2011 the greatly elevated risk for chronic conditions for people with “cognitive limitations.” Using National Health Interview Survey data, Dixon-Ibarra and Horner-Johnson (2014) documented adults with life-long disabilities (acquired before age 6) to be at 2-3 times greater risk for chronic heart disease, cancer, diabetes, obesity and

hypertension. The first author was directing the CDC's Division of Health and Disabilities when these data were published and they were powerful incentives to direct greater federal attention to chronic conditions as a health threat for people with disabilities.

Progress—Data to Document Change

Unfortunately, there are not yet good indicators to track progress in health of IDD populations. This differs from data on place of residence, where the number of people living in institutions has been an indicator of progress for de-institutionalization. For health of people with IDD, we are at the starting point of needing to clarify definitions on whom to include in the count, how to assess health, and what key metrics to track over time. Some notable exceptions are use of NCI data to document increase in utilization of preventive screenings by adults with IDD following Medicaid expansion (Stokes et al, 2015). CDC has tracked trends in prevalence of developmental disabilities over the decades. Using a consistent method—parent report on the National Health Interview Survey with a wide range of diagnostic categories—they have documented trends in different developmental disabilities over time (e.g., Boyle et al, 2011; Zablotsky, et al 2019). Further, Special Olympics is now developing a longitudinal evaluation study to document changes in health of athletes over time. Its initial efforts are modest in sample size and age range (over 18 years) while they develop the protocol to monitor physical, mental, and social health of participants, but they anticipate expanding the evaluation protocol to multiple states and countries in coming years (Lincoln, personal communication, 2024).

The History of Federal Agencies Collaborating for Better IDD Health Data

Surgeon General "Closing the Gap" Report

At the end of the last century, Special Olympics International was effective in bringing the plight of poor health, poor health care, and poor health promotion for persons with IDD to the attention of the Surgeon General's office. Following a series of public hearings across the country, Surgeon General Thatcher issued the *Closing the Gap* report (USDHHS, 2002), a high visibility report that documented the health differences of people with ID and described strategies for improving their health. Among its recommendations was a call for improving data on health of people with IDD. As the last report issued by Thatcher as Surgeon General and with a change in administration, the report appeared to lie nascent for several years. European researchers, in the meanwhile, were publishing on the Pomona project, a multi-country study documenting health status and needs of persons with ID.

First Improved IDD Health Data Plan via CDC

In 2009 CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) convened a post-meeting at an IASSID conference, inviting 24 key researchers from the US and Canada to participate in a planning meeting. The purpose of the meeting was to plan how to improve population health data of persons with IDD by addressing three questions: 1) whom to focus on (definition), 2) what data to collect (indicators), and 3) options for how to gather the data (methodology). Eric Emerson was an invited commenter. After listening to vigorous and disparate debate on specialty services and clinical care, he observed that, if we intended to present issues within a health disparities framework, we needed to focus on core indicators that were relevant to the general population. That crystallized focus and direction for subsequent discussions. As important, perhaps, was that participants expressed a renewed optimism that we could indeed tackle this major problem. Subsequent small group work, and

meetings with policy advocates and federal agencies resulted in a 2010 paper that outlined a 5-step process to improve health surveillance of adults with ID in the US. These steps were to operationally define ID, 2) synthesize the current knowledge base, 3) extend past analyses of existing data, 4) pilot state or regional demonstrations, and 5) expand surveillance nationally. Steps one through four were achieved over the next few years, largely through small grants administered by CDC (Fox, Bonardi & Krahn, 2015). These included a recommended operational definition for IDD (Bonardi et al, 2011) and a multistate Medicaid examination of IDD health on different topics (e.g., McDermott et al, 2018). It was joked that "and then magic happens" would be needed to get to Step 5.

Second Plan: IDD Counts!

In early 2016, the Administration for Community Living (ACL) convened a group of experts to identify prevalence of IDD with the intent to inform ACL's allocations of state funding. The discouraging conclusion of those deliberations was that there really were no valid and recent data to inform estimates of IDD prevalence. As a result, ACL initiated the *IDD Counts!* project to develop a Roadmap for Improved Health Equity Data for people with IDD. An effort of a small work group, it includes national disability organizations, researchers, and agency personnel and a Federal Interagency Workgroup. There was no allocated funding, but it had the commitment from ACL leadership and essential engagement from the National Center for Health Statistics (NCHS) and NCBDDD. All three authors have served as ongoing consultants.

This Roadmap deliberately picked up on the previous 5-step plan, bringing the magic to achieve Step 5 of the previous plan and creating the strategic directions for the next decade. It identifies actions in five areas: enhanced partnerships, surveillance data, administrative data,

expanding capacity for analysis, and data use and dissemination. The plan has been flexible and remarkably robust. Three Summits—in 2017, 2019, and 2022—brought input from advocacy organizations, other federal agencies, and increasingly the voices of adults with IDD. Their input has validated the Roadmap in terms of direction and enriched it in focus and personal meaning.

The Roadmap relies on leveraging partnerships. An important partnership is with NCHS to address the objective for surveillance data. NCHS has been a key collaborator in this work to develop a question set that would better capture the functional limitations identified in the DD Act to use as IDD-identifier questions on the NHIS and other surveys. Key areas were identified for additional questions on the NHIS in order to identify persons with IDD (Havercamp, et al, 2019). For the past few years, a sub-unit at NCHS has cognitively tested different questions on learning, independent living, and social participation with persons with IDD. This work has illustrated the importance of "what's in a question" in determining how wording affects understanding, what associations are generated, and which questions seem to support self and proxy-identification of IDD in persons with documented IDD.

Another area of the Roadmap focuses on harvesting information from administrative data. The report from a second workgroup spoke to the promise and variability of administrative data in informing health status and health needs of persons with IDD (Bonardi, et al, 2019). Efforts are currently underway to determine views on a potential Center of Excellence or Coordinating Center on IDD Health Equity Data. Supported through ACL and CDC, listening sessions and interviews are being used to gather input from different groups about their views on the central role and responsibilities for such a potential center.

Patient Centered Outcomes Research Reauthorization of 2019

Initially, the ID/DD Counts group worked almost sub rosa, but that initial work was very timely. *ID/DD Counts!* laid invaluable groundwork that was available to immediately inform planning when other opportunities arose. And they did! Established through the ACA in 2009, the Patient-Centered Outcomes Research Institute (PCORI) is a nonprofit organization that funds research to help patients and their caregivers make better healthcare decisions. In 2019, Congress reauthorized the PCORI for another ten years and, importantly, the 2019 reauthorization identified persons with IDD as a new research priority. This opened up funds for research on person-centered outcomes and separate funding for federal agencies to build infrastructure. That has brought the much-needed attention of other agencies to health of persons with IDD. Using PCOR-Trust Fund resources, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) has commissioned work resulting in two reports to date. These reports summarize views of a range of experts and identify priorities. Additional reports are anticipated.

Emerging Developments

This is a time of exciting new developments, including several described below.

State implementation. One group that is advancing disability identification at a systems level is the Oregon Health Authority. Under the leadership of Marjorie McGee, they now include mandatory disability identifier questions for health plans that report to the OHA. These questions include the ACS-6 plus additional questions on learning, communication, mental health, and self-identity. They are conducting preliminary analyses of initial data and more information should be forthcoming with additional rounds of data. Importantly, this effort demonstrates that inclusion of disability identifiers can be implemented at the state level,

provides guidance about how it can be done, and will provide estimates of disability based on difficulty learning.

Syndromic Surveillance. Another method for identification has been funded by CDC and undertaken by the Association of State and Territorial Health Officers (ASTHO, 2022). In times of public health emergency, a syndromic surveillance system uses diagnoses in health records to identify and notify people at risk This method begins with the diagnostic codes and keywords from records and develops a set of criteria to identify people with disabilities. Using an iterative process of expert input, webinar audience input, and smaller workgroups, the project has created and tested criteria to identify different types of disabilities, including IDD (see ASTHO, 2022).

Data linking and harmonization. In data linking, data from one data set can be added to that of another to create new information. One dataset may have identifying information on IDD (e.g., education records, registry) that through unique identifiers or probabilistic matching can pull information for each individual with IDD from another data set (e.g., health care utilization). Much of the data linking research for IDD currently comes from Australia and Canada. For example, Lloyd and colleagues recently documented via data linkage that persons with ID who participate in Special Olympics experience depression at only half the rate of other persons with ID not in Special Olympics (Lloyd et al, 2022). Data harmonization refers to trying to synthesize findings across different data sets. For example, the current authors are developing a conceptual process for capitalizing on available but imperfect data. To create an overall picture, the method would build a “data mosaic” on health that would consider which

groups of participants are captured in each data set, the credibility of the data set, and how the relative findings can be patched together to provide new information.

Topics for Health Indicators. To determine priorities for health data collection, ACL sought input from adults with IDD, researchers and clinicians, and family members. The findings indicated some commonalities across all groups (e.g., the need for society to value people with IDD, access to quality care) and noted differences among groups. Adults with IDD called out attention to trust and privacy, the social context, discrimination, and need for neutral supports.

T-MSIS. Medicaid is the public insurance system that provides coverage for the large majority of adults with IDD in the U.S. In recent years, through the Transformed Medicaid Statistical Information System files (T-MSIS) and the Medicare Beneficiary Summary files, researchers can access these data sets. The potential appears great but cost of accessing the system is complicated and expensive. Rubenstein and colleagues have compiled T-MSIS data across states on beneficiaries with ID and Down syndrome. Their analyses are beginning to reveal important information about demographic characteristics and health care utilization (Rubenstein, et al, 2023; Rubenstein et al, 2024).

Intersectionality approaches consider the compounded impact of disability with one or more other identities like race or LGBTQ+ identity. Earlier work noted different prevalence rates of people with disability and IDD by race (Bershadsky, et al, 2014). More recent intersectional approaches work to understand the compounding of life experience of people at the intersections of marginalized identities and how these multi-marginalized identities impact health data (e.g., Hassiotis, 2020).

Self-report and Inclusive research. Some researchers are engaging directly with persons with IDD rather than their proxies to develop, collect, and interpret data. These inclusive research practices include working with people with IDD as key informants, conducting inclusive research with persons with IDD as co-researchers (e.g., O'Brien et al, 2022), and developing processes and competencies needed for inclusive research. For example, Schwartz and colleagues have developed research ethics training that is accessible to persons with IDD (Schwartz et al, 2024) to support them in serving as co-researchers. Others are advocating for and demonstrating the ways in which data can be collected directly from persons with IDD rather than proxies (e.g., Shogren et al, 2021). An important development at the federal level is ACL's collaboration with both NCHS and NCBDDD to develop and pilot test questions for adults with IDD to identify their IDD status for use on national surveys. The intent is to develop a minimal question set that could be used on the NHIS and other surveys.

Ableism. Discrimination and stigmatizing biases are getting increased attention in measurement. Iezzoni and colleagues (2021) released findings of physicians and their self-reported competence and confidence in providing care for people with disabilities generally. This type of work turns the looking glass on well-intentioned professionals and raises questions about where and how our own biases may be harmful.

Big Data, AI and LLM. Use of Artificial Intelligence (AI) including Large Language Models (LLM) is pervading most areas of our lives. AI undoubtedly and dramatically affects data about health of persons with IDD. Researchers already use algorithms to match records across data sets in much of the data linking work. Others are recommending harvesting information from text fields to identify persons with IDD. Reports and perhaps recommendations are increasingly

generated by AI. For disability, as in other areas, there are cautionary caveats about the use of AI, especially AI for decision-making and policy-making. Disability advocacy groups are calling for transparency in the algorithms as they relate to disabilities. The concern is that when marketing groups infer disability status based on purchase histories or social media posts without validating their impressions, and then generate models for private and public users, people with disabilities and other marginalized groups will be harmed. Disability voices are needed in AI development and in AI monitoring groups to challenge stereotypes and decisions before harm occurs.

Conclusion

The journey towards improved health equity data for people with IDD has been ongoing for at least a quarter of a century. Recent developments are very promising to address prevalence, health status, and health needs of people with IDD. Even as we move forward enthusiastically with access to epidemiologic and AI methods, we are reminded to stay focused on the key issues for this population.

- ***Alice**: Would you tell me, please, which way I ought to go from here?*
- ***The Cheshire Cat:** That depends a good deal on where you want to get to.*
- ***Alice:** I don't much care where.*
- ***The Cheshire Cat:** Then it doesn't much matter which way you go.*
- ***Alice:** …So long as I get somewhere.*
- ***The Cheshire Cat:** Oh, you're sure to do that, if only you walk long enough.*

  Lewis Carroll, Alice *in Wonderland*

References

Anderson, L. L., Larson, S. A., MapelLentz, S., & Hall-Lande, J. (2019). A Systematic Review of U.S. Studies on the Prevalence of Intellectual or Developmental Disabilities Since 2000. *Intellectual and Developmental Disabilities*, *57*(5), 421–438. https://doi.org/10.1352/1934-9556-57.5.421

Association of State and Territorial Health Officials. (2022). *Defining disability for syndromic surveillance*. https://www.astho.org/topic/brief/defining-disability-for-syndromic-surveillance/

Bershadsky, J., Hiersteiner, D., Fay, M. L., & Bradley, V. (2014). Race/Ethnicity and the Use of Preventive Health Care Among Adults With Intellectual and Developmental Disabilities. *Medical Care*, *52*(Supplement 3), S25–S31. https://doi.org/10.1097/MLR.0000000000000130

Bonardi, A., Lauer, E., Lulinski, A., Fay, M. L., Morris, A., Nygren, M. A., & Krahn, G. (2019). Unlocking the Potential of State Level Data: Opportunities to Monitor Health and Related Outcomes in People with Intellectual and Developmental Disabilities. *Intellectual and Developmental Disabilities*, *57*(5), 390–404. https://doi.org/10.1352/1934-9556-57.5.390

Boyle, C. A., Boulet, S., Schieve, L. A., Cohen, R. A., Blumberg, S. J., Yeargin-Allsopp, M., Visser, S., & Kogan, M. D. (2011). Trends in the Prevalence of Developmental Disabilities in US Children, 1997–2008. *Pediatrics*, *127*(6), 1034–1042. https://doi.org/10.1542/peds.2010-2989

Cantor, M. N., & Thorpe, L. (2018). Integrating Data On Social Determinants Of Health Into Electronic Health Records. *Health Affairs*, *37*(4), 585–590. https://doi.org/10.1377/hlthaff.2017.1252

Dhopeshwarkar, R., Jiménez, F., Ryan, S., Plourde, E., & Karimi, M. (2024). Improving Data Infrastructure for Person-Centered Outcomes Research on Intellectual and Developmental Disabilities. *American Journal on Intellectual and Developmental Disabilities*, *129*(3), 231–241. https://doi.org/10.1352/1944-7558-129.3.231

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*, 130251. https://doi.org/10.5888/pcd11.130251

Emerson, E., & Glover, G. (2012). The "transition cliff" in the administrative prevalence of learning disabilities in England. *Tizard Learning Disability Review*, *17*(3), 139–143. https://doi.org/10.1108/13595471211240988

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. (2003). Continuum of intellectual disability: Demographic evidence for the "Forgotten Generation." *Mental Retardation*, *41*(6), 420–429.

Hassiotis, A. (2020). The Intersectionality of Ethnicity/race and Intellectual and Developmental Disabilities: Impact on Health Profiles, Service Access and Mortality. *Journal of Mental Health Research in Intellectual Disabilities*, *13*(3), 171–173. https://doi.org/10.1080/19315864.2020.1790702

Havercamp, S. M., Krahn, G. L., Larson, S. A., Fujiura, G., Goode, T. D., Kornblau, B. L., & the National Health Surveillance for IDD Workgroup. (2019). Identifying People with Intellectual and Developmental Disabilities in National Population Surveys. *Intellectual and Developmental Disabilities*, *57*(5), 376–389. https://doi.org/10.1352/1934-9556-57.5.376

Iezzoni, L. I., Rao, S. R., Ressalam, J., Bolcic-Jankovic, D., Agaronnik, N. D., Donelan, K., Lagu, T., & Campbell, E. G. (2021). Physicians' Perceptions Of People With Disability And Their Health Care:

Study reports the results of a survey of physicians' perceptions of people with disability. *Health Affairs*, *40*(2), 297–306. https://doi.org/10.1377/hlthaff.2020.01452

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

Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons With Disabilities as an Unrecognized Health Disparity Population. *American Journal of Public Health*, *105*(S2), S198–S206. https://doi.org/10.2105/AJPH.2014.302182

Larson, S. A., Butterworth, J., Winsor, J., Tanis, S., Lulinski, A., & Smith, J. (2021). *30 years of community living for individuals with intellectual and/or developmental disabilities (1987-2017)*. Administration for Community Living, U.S. Department of Health and Human Services.

Larson, S. A., Lakin, K. C., Anderson, L., Kwak, 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.

Lincoln, A. (2024, July 7). *Personal Communication on Project ALL STAR* [Personal communication].

Lloyd, M., Temple, V. A., Foley, J., Yeatman, S., Lunsky, Y., Huang, A., & Balogh, R. (2022). Young adults with intellectual and developmental disabilities who participate in Special Olympics are less likely to be diagnosed with depression. *Social Psychiatry and Psychiatric Epidemiology*, *58*, 1699–1708.

McDermott, S., Royer, J., Cope, T., Lindgren, S., Momany, E., Lee, J. C., McDuffie, M. J., Lauer, E., Kurtz, S., & Armour, B. S. (2018). Using Medicaid Data to Characterize Persons With Intellectual

and Developmental Disabilities in Five U.S. States. *American Journal on Intellectual and Developmental Disabilities*, *123*(4), 371–381. https://doi.org/10.1352/1944-7558-123.4.371

Mitra, M., Long-Bellil, L., Moura, I., Miles, A., & Kaye, H. S. (2022). Advancing Health Equity And Reducing Health Disparities For People With Disabilities In The United States: Study examines health equity and health disparities for people with disabilities in the United States. *Health Affairs*, *41*(10), 1379–1386. https://doi.org/10.1377/hlthaff.2022.00499

O'Brien, P., Garcia Iriarte, E., Mc Conkey, R., Butler, S., & O'Brien, B. (2022). Inclusive Research and Intellectual Disabilities: Moving Forward on a Road Less Well-Travelled. *Social Sciences*, *11*(10), 483. https://doi.org/10.3390/socsci11100483

Office of the Surgeon General (US), (2002). *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation: Report of the Surgeon General's Conference on Health Disparities and Mental Retardation.* US Department of Health and Human Services. https://www.ncbi.nlm.nih.gov/books/NBK44346/

President's Committee on Mental Retardation. (1999). *The Forgotten Generation*. U.S. Department of Health and Human Services, Administration for Children and Families.

Reichard, A., Stolzle, H., & Fox, M. H. (2011). Health disparities among adults with physical disabilities or cognitive limitations compared to individuals with no disabilities in the United States. *Disability and Health Journal*, *4*(2), 59–67. https://doi.org/10.1016/j.dhjo.2010.05.003

Rosencrans, M., Tassé, M. J., Kim, M., Krahn, G. L., Bonardi, A., Rabidoux, P., Bourne, M. L., & Havercamp, S. M. (2021). Invisible populations: Who is missing from research in intellectual disability? *Research in Developmental Disabilities*, *119*, 104117. https://doi.org/10.1016/j.ridd.2021.104117

Rubenstein, E., Michals, A., Wang, N., Scott, A., Tewolde, S., Levine, A. A., Tripodis, Y., & Skotko, B. G. (2023). Medicaid Enrollment and Service Use Among Adults With Down Syndrome. *JAMA Health Forum*, *4*(8), e232320. https://doi.org/10.1001/jamahealthforum.2023.2320

Schwartz, A., & McDonald, K. (2024). *Research Ethics for All (Re4ALL), https://iod.unh.edu/research-ethics-all-re4all*. https://iod.unh.edu/research-ethics-all-re4all

Shogren, K. A., Bonardi, A., Cobranchi, C., Krahn, G., Murray, A., Robinson, A., Havercamp, S. M., & The Nisonger RRTC on Health and Function. (2021). State of the Field: The Need for Self Report Measures of Health and Quality of Life for People With Intellectual and Developmental Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *18*(4), 286–295. https://doi.org/10.1111/jppi.12386

Stevens, A. C., Courtney-Long, E. A., Okoro, C. A., & Carroll, D. D. (2016). Comparison of 2 Disability Measures, Behavioral Risk Factor Surveillance System, 2013. *Preventing Chronic Disease*, *13*, 160080. https://doi.org/10.5888/pcd13.160080

Stokes, J. E., Waldron, D. A., Hartford, E. G., & Sauer, J. (2023). Preventive Healthcare Screening Completion Among Midlife and Older Adults With Intellectual and Developmental Disabilities. *Journal of Applied Gerontology*, *42*(12), 2288–2293. https://doi.org/10.1177/07334648231191663

Zablotsky, B., Black, L. I., Maenner, M. J., Schieve, L. A., Danielson, M. L., Bitsko, R. H., Blumberg, S. J., Kogan, M. D., & Boyle, C. A. (2019). Prevalence and Trends of Developmental Disabilities among Children in the United States: 2009–2017. *Pediatrics*, *144*(4), e20190811. https://doi.org/10.1542/peds.2019-0811

Figure

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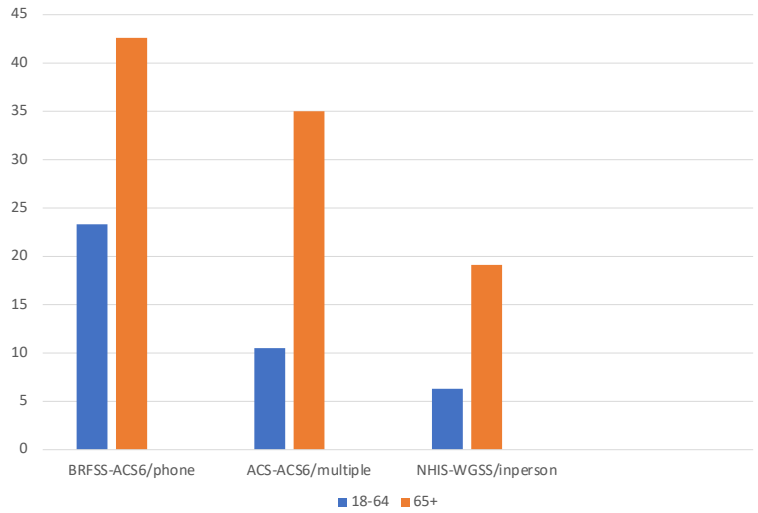
Figure 1. Comparison of Disability Estimates by Survey Modality and Questions ~2019



Response Rates
BRFSS 31-64%
ACS 94.7%
NHIS 61%

Surveys:
Behavioral Risk Factor Surveillance System
American Community Survey
National Health Interview Survey

Data from Mitra, Long-Bellil, Moura, Miles & Kaye, 2022; Websites for BRFSS, ACS, NHIS for response rates

Table 1. Expansion of health indicators for people with IDD over time

Time frame	**Categories**	**Indicators**
Pre-1980's	Mortality and Morbidity	Life expectancy
		Chronic diseases
		Injuries
~1990's	Quality of Life	Health care access
		Self-reported health
		Psychological distress
		Self-determination
~2000's	Health Behaviors	Smoking
		Excess drinking
		Physical activity and sedentary behavior
		Nutrition
~2010's	Environment (Social Determinants)	Safety and physical access
		Place of residence
		Ableism and Discrimination