

FEDERAL DISABILITY SURVEYS IN THE UNITED STATES: LESSONS AND CHALLENGES

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INTRODUCTION

We are here, because attention needs to be called to how we can measure a subjective (and many times political) measure in a scientific way. We need a short set of valid, reliable disability indicators for those under age 65 that can be routinely included on population surveys. Although there have been many efforts, no one has found the “Holy Grail”. Yet we have made progress, particularly during the last decade.

Disability is one of the most critical data elements needed for Federal programs and policy, but perhaps the hardest to measure and define. Thus, disability measurement and research are difficult, but necessary challenges.

Disability is a key policy concern. Approximately 40 million Americans report a disability. In addition, there are dozens of disability programs in the U.S., each with a different purpose. Examples of federal programs include special education for children, Black Lung benefits for coal miners with pneumoconiosis, and SSA’s Disability Insurance (DI) program that provides monthly cash benefits to insured workers who meet certain disability criteria. Altogether, there are 43 different programmatic ways to define disability for federal programs in the U.S. This year in the U.S., we are celebrating the tenth anniversary of the Americans with Disabilities Act (ADA), which provides civil rights protections to people with disabilities.

Before beginning any kind of disability measurement, research, or analysis two questions crop up again and again, but must be addressed.

- How exactly is disability defined?
- “Disabled” in what regard?

PURPOSE

This paper explores recent history of disability measurement in the U.S. federal statistical system. Disability measurement is complex, because

disability is so all encompassing. Although there are many measurement challenges in disability, four universal challenges faced by nearly every disability survey effort are selected: (1) duration and periodicity, (2) severity, (3) mental illness and cognitive impairments, and, (4) disability in children.

Each challenge is discussed generally, then specific approaches from each of four major surveys are described, and finally solutions and unmet challenges are presented. The four major Federal surveys include:

- Surveys of Income and Program Participation (SIPP) – A longitudinal survey administered by the Census Bureau through in-person interviews. Disability has never been a primary purpose of SIPP, but this survey has nevertheless been a valuable source of data. A disability module was first included in Wave 3 of the 1983 Panel and sporadically thereafter until the 1990 Panel when disability became a mainstay on Waves 3 and 6 that occur one year apart.
- 1990 Decennial Census – Three disability questions were included on the long form of the 1990 Census for persons aged 16 and over. One question asked about the ability to work, another about the ability to take care of one’s personal needs, and the third about the ability to get around outside the house. The Decennial Census was administered largely by mail back procedures.
- 2000 Decennial Census – Six disability questions were included on the long form. Respondents aged 16 or over were asked the question from the 1990 Census on the ability to get around outside along with an abbreviated item on work. Respondents aged 5 and over (including children) were asked questions on physical functioning, sensory and cognitive impairments, and the 1990 item on self-care. Mail back procedures were used for the 2000 Census.

¹ Any opinions expressed in this paper are those of the authors and do not reflect the view of the Social Security Administration nor the Centers for Disease Control.

- National Health Interview Supplement on Disability (NHIS-D) – The NHIS-D (1994-97) was the first comprehensive U.S. national disability survey. All ages (from birth) were included. Two in-person interviews were administered. The first interview contained about 80 items that identified disability. The second interview, administered to those identified as having serious disabilities², collected information on aspects of daily life (i.e. employment, housing, transportation, services).

The SIPP and the NHIS-D covered the civilian non-institutionalized population, whereas the 1990 and 2000 Decennial Censuses included the entire resident population, including those in institutions. The four surveys were not designed in a vacuum. Work from one has a direct impact on the others and there has been and will continue to be a great deal of interaction.

DEFINITIONAL OVERVIEW

What is disability? No single accepted definition exists and no single definition probably ever will. Functions vary by what society dictates that an individual is “supposed to do” depending on age, sex, and culture. In general, children are expected to learn, grow, and develop; working-age adults to work; and, elderly adults to live independently. Typically, disability refers to a limitation or inability to perform certain functions due to a medical condition. This generic definition can be separated in three parts:

“...*limitation or inability*...” It is important to note that disability can include both limitations (which mean that there is some functioning) and inabilities. Furthermore, individuals with limitations and/or inabilities also have abilities – the flip side of disability. Focusing just on disability can give a distorted view.

“...*to perform*...” The notion of performing functions is complicated, as the environment is a key factor. A person who could easily get around using a wheelchair may not be able to do so without

one. Another person may be able to bathe, but only with the assistance of grab bars or a personal assistant.

Thus, the environment can determine functioning. The role of the environment is becoming more critical as numerous assistive devices enter the marketplace every day. Technology, particularly computers, is changing how we live, how we work, and how we view physical functioning. The environment shows signs of continuing to rapidly change. This will continue to have a direct impact on what we mean by disability and how we measure it.

“...*certain functions*...”: Functions can be physical (i.e. lifting, climbing, walking), sensory (i.e. hearing, seeing), cognitive (i.e. learning, remembering), or mental/emotional (i.e. moods, interactions). There are more complicated self-care functions (i.e. bathing, eating, cooking, doing light housework, managing money). Sometimes many functions are grouped together into “roles” (e.g. working, attending school, and keeping house).

“...*due to a medical condition*...”: Disabilities result from medical conditions, but medical conditions do not always result in disabilities. (It is important to note that the perception of disability – even in the absence of a medical condition - is defined as one under both the ADA and ICIDH definitions.) Disabilities can have a sudden onset along with the medical condition (e.g. loss of a limb in an accident), a gradual onset (e.g. multiple sclerosis), or a series of episodic onsets (e.g. cancer and mental illness). Generally, the more prevalent the medical condition, the less likely it is to result in disability. For example, the most prevalent chronic condition, according to the (old) Current Estimates from the National Health Interview Survey (NHIS) was sinusitis – a rarely disabling condition. (LaPlante) Furthermore, no medical condition – no matter how severe – always results in a disability. According to the NHIS-D, approximately 93 percent of those with mental retardation and other conditions commonly referred to as developmental disabilities actually report a disability that is a limitation or inability to perform one or more functions.

It has long been acknowledged that disabilities do not include limitations or inabilities to perform functions for non-medical reasons.

² The selection algorithm was complex. Given the lack of information about and the low prevalence of disability among children and young adults, the selection algorithm resulted in the inclusion of some children and young adults with mild or moderate disabilities into the second interview.

There are other ways to measure disability besides functioning. For example, for programmatic purposes, an individual is classified as having a disability if he or she receives disability benefits. There is also perception of disability – a notion resulting from the ADA. Measures of perception of disability, either self-perceived or perceived by others, were used in the NHIS-D, because these concepts are at the heart of the ADA. This measure will make it easier to understand the effects of the ADA.

Disability prevalence varies depending on the definition used. According to the 1994 NHIS-D, 25.7 million working-age (18-64) individuals (out of 158.6 million) had reported a functional disability (of whom 5.3 million reported ADLs and/or IADLs), 16.9 million reported limitations in work, 9.1 million received disability benefits, and 11.1 million were perceived by themselves or others as having a disability. (Adler, 11/96)

CHALLENGES

NUMBER ONE - Duration and Periodicity: Most disability programs cover only those with long-term disabilities. The largest disability programs –SSDI, SSI, Medicare, and Medicaid - have a duration requirement that "...a disability should last or be expected to last at least 12 months or end in death..". The State Workers' Compensation programs cover both long and short-term disabilities resulting from injuries or accidents at work. Examples of short-term disabilities are fractures that take 6-8 weeks in a cast or the inability to take care of oneself for a month or so after a knee replacement.

Duration was handled in different ways in the four surveys. The SIPP questions are a mixture of no duration requirements ("does ... have difficulty lifting 10 lbs.??") and a "long-lasting" requirement (for the ADLs and IADLs). The 1990 Census includes only long lasting (i.e. at least 6 months), while the 2000 Census is mixture of no duration and "long lasting". The NHIS-D asks about disabilities, first with no duration, and then with a duration "...lasting or expected to last at least 12 months", in accordance with SSA's disability programs.

During the design phase of the NHIS-D, work was done to obtain information on duration. However work in the Pretest and in the NCHS Cognitive Questionnaire Lab indicated that respondents are frequently unable to report onset, especially when

onset occurred either gradually or in an "up and down" pattern. Therefore, duration was limited to determining whether or not the disability lasted or was expected to last 12 months or had occurred before age 22. The latter data element was needed in order to determine the legislative definition for respondents with "developmental disabilities".

Thus, the impact of duration on disability can be measured using the NHIS-D. Duration makes a big difference in the number and characteristics of people with disabilities. According to the 1994 NHIS-D, if both acute and chronic disabilities are included, an estimated 75 million Americans (of all ages) reported a functional disability, but the estimate drops to 47.6 million if only long-term disabilities are included.

NUMBER TWO - Severity: Severity is a critical concern, because interventions (and thus treatment and maintenance plans, rehabilitation, prognoses, and programs) vary greatly depending on how severe a disability is. At first, severity seems like a simple concept. In fact, it is for federal programs, which are typically built on the premise that those eligible for programs have a severe disability, while those who are not, do not have a disability. But while severity is a crucial program and policy concern, it very complicated as a practical matter.

Severity can be relatively easy to determine for a specific disability. For example, an inability to climb stairs is more severe than difficulty climbing stairs. Certain functions are more necessary than others are, so a disability in one function can be more severe than in another. For example, either difficulty with or the inability to eat (without the help of another person) is more severe than inability or difficulties with heavy housework or yardwork.

Severity becomes conceptually and analytically difficult when more than one function is examined. Sometimes a person with many difficulties can be as disabled as one with one inability. Although there are health scales, there are few that pertain to disability and fewer still that include mental, sensory, and physical impairments.

The Activities of Daily Living (ADLs) were constructed by Katz for the frail elderly (aged 85 or over). The ADLs are defined as the inability or difficulty (without the help of another person) to perform self-care tasks such as bathing, eating, getting to and using the toilet, transferring from bed

to chair, dressing, and getting around inside the house. The ADLs were constructed with a natural hierarchy with eating as the most severe ADL. Much research has been done on the ADLs within the context of the frail elderly. ADLs have been shown to be significant indicators of admission to nursing homes or hospitals and even death. Severity is not only defined by the hierarchy, but by the number of ADLs present. The more ADLs, the more severe the disability. (Weiner et al)

An advantage of ADLs is that they are so easy to understand and use as a severity measure. ADLs are often misused (particularly for the non-elderly), because mental and cognitive deficits may not be adequately taken into account.

The advantage of SIPP and the NHIS-D is that there are so many questions, there is a great deal of freedom to construct appropriate measures. The disadvantage is that there are so many questions and thus so many decisions to make. In SIPP, a series of questions ask first about limitations (difficulties). If respondents answer positively, there are then asked about inabilities.

*“Does ...have difficulty lifting 10 lbs.? “
If yes, “Is ...able at all to lift 10 lbs?”*

There are over a dozen sets of questions such as this one in SIPP. Severity can be defined in many ways. McNeil originally defined severity as having at least one inability or more than one difficulty, but has since incorporated factors such as the presence of certain reported conditions (i.e. mental illness). Adler used six levels of severity for an analysis of 1984 SIPP data for the working-age population: Level I - inability to perform ADLs without the assistance of another person (1.7 percent); Level II - inability to perform IADLs without the assistance of another person (2.8 percent); Level III - either an inability to perform more than one of the following activities (seeing, hearing, lifting 10 lbs., walking three city blocks, or climbing a flight of stairs) or difficulty with two ADLs without needing personal assistance (4.4 percent), Level IV- no inabilities, but difficulties with two or more of the following activities (seeing, hearing, lifting 10 lbs., walking three city blocks, or climbing a flight of stairs) (4.8 percent), Level V - difficulty with only one of the following activities (seeing, hearing, lifting 10 lbs., walking three city blocks, or climbing a flight of stairs) (8.2 percent); and Level VI - no reported difficulties (78.1

percent). Many different ways to measure severity have been constructed since.

The NHIS-D is more complicated, as there are 80 questions presented in this “difficulty/inability” mode. The NHIS-D was envisioned as a data set where many different measures of disability and severity could be tailored for specific analytical uses. However, general usage can be fraught with difficulty.

The 1990 and 2000 Censuses are easier to analyze, because difficulties and inabilities are not distinguished. However, severity measures can still be constructed based on the number and type of disabilities reported.

NUMBER THREE - Mental Illness and Cognitive Impairments: Mental illness is the most prevalent condition for young adults under 45 to receive SSI. In 1994, of the 23.5 million working-age Americans reporting mental illness, only 5.1 million were so severely disabled that they had serious limitations in their ability to do work or perform day-to-day activities during the past year AND reported limitations in ADL and/or IADLs. (Adler, November 1996) Mental illness is episodic, so duration must be included in measurements. Mental health researchers and clinicians often refer to “serious chronic” mental illness.

It is hard to separate mental illness from mental health. For example, clinicians define depression after the loss of a spouse or child as “normal” if it lasts for only two months or if no severe behaviors (suicide attempt) occur during that time. The plethora of prescription drugs for mental illness has resulted in many previously disabling mental impairments to be less severe. However, many individuals need their drugs to be continually monitored and readjusted. If not, mental illness can become severely disabling.

Despite the high prevalence of mental illness, a stigma remains, making it harder for surveys to gather self-reported data. Proxy respondents are also a concern, because a respondent may be so seriously mentally ill that he or she cannot respond for himself and because the proxy respondent may not know how the person with mental illness is actually feeling. For individuals with very severe mental illness, symptoms like the delusions and the inability to understand time (historical inadequacy) are the very qualities that render them unable to accurately respond to surveys.

Mental illness measures are less evolved than other aspects of disability. For many years, mental illness was not included in disability measures as it was thought to be too difficult to measure and too sensitive to even ask.

SIPP has undergone changes over the years on how mental illness and disability is ascertained. In 1990, some major changes were made. An important step was made when an introductory phrase developed by the National Medical Expenditure Surveys was included for the ADLs and IADLs. This phrase read "Because of a physical, mental, or emotional health condition..." It was ascertained NCHS' cognitive lab that ADL on eating item had been reported primarily by individuals who had trouble swallowing, chewing, cutting their food, and/or using utensils for physical reasons, but did not include those whose difficulties were due to mental impairments (i.e. paranoid individuals who could not eat for fear of poison).

Secondly SIPP included a series of questions in the disability module in which respondents were asked if they had "... mental illness, mental retardation, Alzheimer's, a learning disability, or a developmental disability (like cerebral palsy)". It is important to note that the condition was ascertained, but no link to disability was made with this approach. Thirdly, in its item on hospital stays, SIPP separated hospitalizations due to mental illness from those due to surgery, childbirth, or other medical conditions. It is widely acknowledged that individuals with a hospital stay for mental illness have a serious chronic mental illness.

The 1996 SIPP abbreviated the series of questions developed for adults from the NHIS-D, which were derived from the 1991 NHIS Supplement on Mental Illness, which in turn were developed from the American Psychiatric Association's SCID – a uniform diagnostic tool. The NHIS-D approach was to address the stigma. Much of this work was done in the NCHS cognitive lab. Various aspects of mental illness were included: a list of diagnoses (i.e. schizophrenia, bipolar), a list of symptoms (i.e. FREQUENTLY depressed, unable to concentrate), and whether or not prescription drugs were used. For those who indicated at least one item, a question "did ... seriously interfere with your work or day-to-day activities during the last year?". This question distinguished between those with mental

illness and those with mental disabilities. The receipt of routine counseling was also asked.

Cognitive impairments are also difficult to ascertain in surveys for many of the same reasons as mental illness. Alzheimer's and related dementias are the most common cognitive impairments in the elderly and much research has been done. Less research has been done on the cognitive impairments among the non-elderly, which primarily consist of mental retardation, traumatic brain injury, and learning disabilities.

Some symptoms are the same for mental illness and cognitive impairments (i.e. confusion, unable to remember, lack of concentration) and some disabilities are the same. The IADLs, a series of cognitive activities that enable one to deal with the outside world, include: shopping, cooking, doing light housework, doing heavy housework, using the telephone, getting around outside, managing money, and managing medication. While those with ADLs resulting from physical impairments may also report IADLs, typically those who report IADLs (but no ADLs) have mental or cognitive impairments. It is tempting to create severity measures by simply counting the number of ADLs and IADLs. Less of a hierarchy exists for IADLs. Furthermore, some IADLs are not performed for non-medical reasons.³ For example, a man who cannot prepare meals, because he never learned to cook or a wealthy individual whose money is handled by a financial manager do not perform these functions, but not due to a disability.

The identification of mental retardation and other developmental disabilities (MR/DD) according to the legislative definition was a central purpose of the NHIS-D. The prevalence of MR/DD was simply not known. The development of these questions came from an ASPE contract that translated legislative concepts into survey terms. Then these terms were incorporated into the rest of the NHIS-D. In addition to the IADLs, items on learning, remembering, and communicating were added. A list of specific diagnoses (i.e. cerebral palsy, spina bifida) was also included. Finally, since the term developmental disability refers to

³ A conceptual difficulty faced by President Clinton's Health Care Reform effort and other long-term care programs is how to derive an equivalent IADL construct similar to the ADL one used for the frail elderly

disabilities whose onset began before age 22, questions were added to ascertain if the disability occurred prior to that age.

The 1990 census did not include mental illness or cognitive impairments specifically, but the 2000 census has an item on “learning, remembering, and concentrating” which is intended to encompass mental impairments including mental illness and cognitive impairments.

NUMBER FOUR - Children: Disability measurement in children is the least understood and developed aspect of disability. Because disability rates increase so rapidly with advancing age, the prevalence of disability among children is very low. Furthermore, before medical technologies developed as recently as 20 or 30 years ago, children with disabilities did not live to adulthood. Thus, research and measurement was conducted in largely clinical settings. Finally, children were often confined to institutions and did not fall under the purview of population-based surveys.

Disability is hard to measure in children, because there are so many stages to childhood – infants (under age one), toddlers (ages 1-3), preschool (ages 3-5), school age (ages 5 on), and adolescence (ages 13-19). The upper age limit for children has also changed over the years. The CPS uses age 16 as adulthood (i.e. the age at which work can begin) and SIPP uses age 15. Historically, children used to work before child labor laws took effect in the early 20th century. The legal age of adulthood now is age 18. However, special education programs can occur until age 22.

A major measurement concern for childhood disability is that not all developmental differences and delays can be attributed to disability. Children develop a large number of skills prior to adulthood (e.g. large motor skills, fine motor skills, language and communication, social skills, organization, reading and writing, math and calculation, learning, prioritizing). These skills are typically developed simultaneously. It may be common for a child to be ahead in one area (e.g. gross motor) and on par or behind in other areas. There are also gender differences, because boys have a longer maturity and growth cycle than girls. Finally, what is defined as a severe disability in school-age children (dressing) is not considered disabling for those under age 5.

In the 1984 SIPP when two questions on children’s disability were asked – “does your child have a physical disability and does your child have a mental disability?” A slightly longer set was included in the 1990 SIPP and, beginning in 1996, a longer set derived from the NHIS-D was included. Children’s disability was not ascertained at all in the 1990 Census and (as described earlier) was collected for those aged 5 or over for a few items in 2000.

Children’s items in the NHIS-D were carefully developed over a period of years. Results from a grant to Albert Einstein Hospital sponsored by the Maternal and Child Bureau were instrumental in development of these items. All responses were asked of proxy respondents, usually parents. Whenever possible, items were expanded to include all ages (e.g. sensory impairments). The ADL items were asked of all respondents aged 6 or over. The IADLs items limited to those aged 18 or over, as were the physical functioning items and the mental health set. The latter two, however, were tailored for children in their own section.

A series of developmental items --“...does your child have any difficulty in (learning, communicating, or getting along with others, physical development”) --were asked. However, for affirmative responses, a question was added (“...were you told this by a health care professional?”) to distinguish between parents whose children had developmental delays and parents with high expectations.

A series of specific developmental activities was asked for infants and toddlers (under 36 months). Separation was made for roughly 3-month intervals. For example, information on smiling and recognizing parents were ascertained for infants under 3 months of age. Other activities included sitting up, crawling, walking, talking, holding a toy, and using the toilet. The most severe disabilities for young children was derived in conjunction with the American Academy of Pediatrics and measured as not being able to hold up the head by age 1, walking by age 3, and talking by age 5. (Adler)

Physical activities for school-age children included many of those also used for adults with the addition of school behaviors and strenuous activities like running. Mental health measures were tailored for children. For example, the ability to get along with co-workers was replaced by being able to play and get along with other children.

There is still much work to do in the measurement of children's disability. Recent efforts have included scaling and attempts to ask older children directly about their disabilities. (Hogan et al)

CONCLUSIONS

Disability has a number of aspects that make it difficult to measure, but it is so critical that we need to do it anyway. Disability changes over time, often for valid reasons (getting better or worse), so traditional tests may not be appropriate to assess measures. The issue of proxy versus self-respondents is complicated and in some instances proxy respondents may yield more accurate information. Disability is changing as the environment and workplace change. That will only continue. Finally, perceptions of disability are changing as the inclusion of people with disabilities into the mainstream, for political and demographic reasons, increases. Disability measurement is evolving and we are catching up.

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