

Disabled Non-Beneficiaries

Who Work

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Introduction

There are people with disabilities severe enough to qualify them for Social Security Disability Insurance (SSDI) or for Supplemental Security Insurance (SSI) who have never applied. Many who are SSDI eligible continue to be gainfully employed. The problem is that we do not know anything about these medically eligible people; we do not even know how many there are.

We know that less than 100% of the people who are eligible for SSI and SSDI are enrolled; that is true for most social insurance and assistance programs. The resulting pool of nonparticipating eligibles represents the potential for program growth that could result from recessions or other contingencies that might influence the application decision. In addition, both changes in eligibility rules and variation in the strictness or leniency with which the rules are applied can also affect the number of potential eligibles. Thus, monitoring changes in the pool of eligibles ensuing from trends (real or hypothetical) or policy initiatives would add much to our understanding of the disability programs.

Simulations of program eligibility are undertaken routinely for social insurance and welfare programs that are not targeted toward the disabled. For example, a projection of the number of people old enough for Social Security retirement benefits—a straightforward simulation of the non-financial element of eligibility—frequently provides the intellectual backdrop for discussions of Social Security reform.

Prospects for reliable estimates of disability eligibles have always been far less promising. First, medical eligibility for disability programs depends on an agency-specific definition of health status and on ability to work, neither of which is directly observable or verifiable as is date of birth. Surveys are the main source of the information and it is self-reported and subjective. Second, the disability determination process, which compares the applicant's impairment severity and functional capacity to program standards, is also somewhat judgmental and, even though it must be accompanied by a physician's evaluation, much of that evaluation is based on a medical history--which is also self-reported. Third, in addition to the medical eligibility there must be the inability to be gainfully employed and the definition of "gainful" depends on a dollar amount that few people can report. Due to these limitations, it is difficult to assess medical eligibility among non-applicants. This poses a handicap for policymakers because eligibility is the primary means by which they control the targeting of any public program. In addition, although it is not a subject for this paper, eligibility for SSDI includes a history of work that is covered by Social Security.

The policy concern is that there may be significant numbers of such people and that in the

event of an economic slowdown they might apply for SSDI or SSI. Despite the concern, little is known about the disabled people who never applied for either program. The purpose of this project was to learn about these people. The first goal was to ascertain how many there are.

The second goal was to learn about the characteristics of working people with disabilities severe enough to qualify for SSDI, including the factors that enable them to work. One of the SSA goals is to enable people to return to work, but the goal of returning people to work has not been achieved. Once people have left employment and become beneficiaries they remain beneficiaries. It would be far better to help people continue working so they do not have a break in employment. That policy goal has not been achieved either, but we understood very little about what enables some people with severe disabilities to continue working. Their characteristics could be internal or external. They could be a function of education, of individual psychology, of the age at onset of the disability or they could be a function of a support group, or transportation, or special equipment on the job. We need to learn more.

The research approach is three-pronged:

- 1) an annotated review of existing studies,
- 2) an annotated review of existing data sets, and
- 3) an analysis of linked data sets.

This report is on the first two phases of the study. That is the only part for which funding was sought or granted. There are recommendations for the third phase.

Phase I Review of Existing Studies

Results in brief

The intent of Phase I of the project was to conduct a meta-analysis of the studies if there were enough good quality studies. Because one of the criticisms of meta-analysis is the possibility of omitting studies that do not agree with the authors' biases we wanted to err on the side of being overly inclusive rather than risk excluding relevant studies. Therefore, our first search was of every print database and website that we could locate. From those sources we retrieved all studies that contained disability, age, and employment in title, keywords, or text. From those sources we retrieved 94 studies.

We then searched those studies using more restrictive criteria including severity of disability, source of income, and some variables that would be needed for meta-analysis. That search resulted in 26 studies that met most of the criteria. ***However, only one of the 26 studies met all of the criteria.*** The most critical missing item was severity. Only one of the studies used a measure of disability that was close to the Social Security Administration's definition of disability; many just said that the individual was disabled with no definition at all. The second most critical missing item was source of income. Without that information it was impossible to know whether the individual was, or was not, receiving benefits for Social Security Disability Insurance (SSDI).

The study that met the criteria, *Counting the Disabled: Using Survey Self-Reports to Estimate Medical Eligibility for Social Security's Disability Programs* (Dwyer, Hu, Vaughan, & Wixon, 2001), relied on data from the 1990 panel of the Survey of Income and Program Participation linked with Social Security files. After developing models to simulate the DDS determinations the authors concluded that:

Given the analysis, our estimates suggest that 4.4 million people, or 2.9% of the non-beneficiary population aged 18-64, would meet the SSA's medical criteria for disability. Of that group, 3 million (or 2.0% of the population studied) had average earnings below the maximum SGA amount (\$500 per month) in the prior year; that is, they are estimated to be eligible in terms of both SSA's medical criteria and the SGA test. The balance, 1.4 million, are medically eligible but have average earnings above the SGA limit. Some of the latter group would end up on the rolls in the event of a recession.

There is, as far as we can ascertain, no study showing the characteristics of such persons. The study cited above does say,

How do those we estimate to be medically eligible compare to ineligibles?
Based on conventional survey health measures, eligibles are much more impaired and much more frequently work limited. Moreover, they are more likely to be older, unmarried, less educated, poor, and low earners.

Disability

One of the reasons that studies that address the issue of SSDI eligibility do not exist is that there is no universal definition of disability. Authors can, and do, define it for their own purposes. Legislation uses different definitions.

Under the Americans with Disabilities Act, the term "disability" means

- a physical or mental impairment that substantially limits one or more of the major life activities of such individual;
- a record of such an impairment; or
- being regarded as having such an impairment.

A person must meet the requirements of at least one of these three criteria to be an individual with a disability under the Act (1).

One widely-used research measure, based on Katz's Activities of Daily Living, measures ability to live independently and is primarily useful for older people (2). In contrast, disability defined for Social Security Disability Insurance must measure the ability to be gainfully employed.

The definition of disability under Social Security is different than other programs. Social Security pays only for total disability. No benefits are payable for partial disability or for short-term disability. To receive Social Security Disability Insurance (SSDI) an individual must meet the following criteria:

- be under the age 65 yrs;
- be unable to be gainfully employed due to his or her medical condition;
- be unable to do the work that was done before and unable to adjust to other work because of the medical condition; and,
- the medical condition must have lasted or be expected to last at least 12 continuous months or to result in death (3).

Those criteria are difficult to measure. The age criterion is simple but the rest are difficult. The major difficulty is that the disability must be severe enough that the individual cannot be gainfully employed. It is possible to ask a respondent if he (or she) is disabled enough to be unable to work – that is done on the National Health Interview Survey - but how does the respondent know whether he is disabled enough that he cannot be gainfully employed? Or that he is unable to adjust to other work because of the

medical condition? How many people know if they are gainfully employed or that being gainfully employed meant earning \$740 or more per month in 2001 but \$780 or more in 2002?

Methodology

Process

Patricia Cloud, Director of the Sheatsley Library at the National Opinion Research Center (NORC) at the University of Chicago made a list of all the electronic databases and searched them for studies containing the words “disability, age, employment.” She also searched the Proceedings of professional associations that might have papers on the measurement of disability or the prevalence. Carmelita Grady, Consultant to NORC, did the same thing with the websites.

We were deliberately not restrictive in this search. We knew that we would get material that we could not use. However, we did not want to risk missing something that should be included. Despite our endeavor to include everything remotely relevant, that search yielded only 94 studies.

We then reviewed those 94 studies using the criteria listed below. Most of the studies were irrelevant. They were of older people or nursing home residents. Some were studies of methods for training disabled persons to work. In all only 26 studies were worth reading carefully.

Criteria for Item in Studies

Age	Mandatory - SSA requires that one meet the age qualification to receive SSDI benefits. Therefore we are only interested in those who meet the age requirement of 18-64 years of age.
Source of Income	Mandatory – Whether the individual is receiving SSI benefits must be known.
Amount of Income	Mandatory - Individual must meet the “amount of earned income” eligibility criteria (The amount changes with cost of living).
Disability	Mandatory – The purpose of this effort is to identify those disabled who remain gainfully employed.
Severity	Mandatory - The SSA has a very precise definition of the severity that qualifies the individual for benefits. While it may not be

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possible to meet that precise definition in a study, some measure of the severity of the disability must be present.

Gender	Not Mandatory – Gender is not necessary for inclusion but might be useful for review and discussion/comparison.
Confidence Interval	Mandatory - Confidence interval is necessary to combine studies for meta-analysis.
Year of Collection	Desirable - Legislative and other changes occur that impact eligibility requirements.
Mode of Collection	Desirable - Contextual factors influence content. They may also reveal some aspects of the quality of the data.
Respondent	Desirable - Disability may prevent a self-response. The absence of any information may reveal some aspects of the quality of the data.

Results

Citations and summaries for the 26 studies that we reviewed carefully are summarized at the end of the text.

No study had information on the response rates to the underlying data (in a very few cases, such as articles based on record reviews, they may not be appropriate) and no study had confidence intervals, which are essential for meta-analysis.

One item was missing from almost all the studies. With one exception, no study had a measure of the severity of the disability. That study was based in the Survey of Income and Program Participation (SIPP) conducted by the US Bureau of the Census that was linked to SSA records. Even it had flaws. The SSA employed three of the authors of the paper so they understood the disability determination process and were interested in modeling that. They displayed less knowledge about analysis of data from surveys with complex sample designs and about how to determine disability on an interview survey. The SIPP, like all surveys with a complex sample design, requires special software to make population estimates. If the authors used such software, they did not mention it. Throughout the paper, including the title, they wrote of “self-reports” as if all self-reports are alike. They did not acknowledge that the SIPP is not a survey of disability or even a health survey; the purpose is to determine program participation--the disability questions are an added module. The problem is not self-reports, it is the questions, and it is--as the authors say--the disability determination process itself which is not easily replicated on a survey questionnaire. For example, it would be impossible to reproduce the entire

medical listing on a survey.

The point about not all self-reports being alike is important enough to amplify it. The context is critical. As stated above, when a physician takes a medical history that is self-reported. When a clerk takes an application for SSDI that is self-reported. When an interviewer asks questions of a respondent, those answers are self-reported. Whether the same individual would give the same answers in those three situations, we do not know. There has been little research on that issue; one exception is Brehm and Rush (1988), which is discussed in the next section. There has been, however, a vast amount of research on asking questions on surveys, and even within that single environment there are many factors that influence the accuracy of self-reporting. One is the context of the survey. A question on disability asked in the midst of a number of questions on health and use of medical services is likely to get a more-considered reply than one asked in the midst of questions on, say, education and child care. Another is clarity and understanding. It is remarkable how often the designers of questionnaires assume that everyone else thinks as they do. Cognitive research has demonstrated that is just not true (4,5). Questions must be asked so the respondent can understand them, and most respondents do not understand medical terms. Another is the sensitivity of the question. Some questions, such as amount of income, are sensitive to large numbers of people; income is the most frequently unanswered question on a questionnaire. Other questions are sensitive only to certain people. It is possible, for example, that questions on disability that most people would not find sensitive, might be sensitive to someone applying for or receiving disability benefits. It is possible that questions on height and weight will be sensitive to people who feel themselves overweight. But even the wording of the questions may influence the answers. Probably the best, most relevant recent paper on the topic is Rodgers and Miller's (1997) paper (6). It is based on research modules incorporated in the Health and Retirement Survey. Each group of participants received the Activities of Daily Living questions as they were asked on different surveys. Because differences among surveys were eliminated, the differences in the answers could be attributed directly to the difference in the questions. The different wordings did produce different estimates of prevalence.

The second most frequently missing item was the source of income. If the study did not say whether the person received income from SSDI, one could not tell whether he or she was a beneficiary or not. If it did not say that income was from the individual's own employment, one could not tell whether the person was gainfully employed. This study removed that problem by linking with the SSA records; there was no question that the individual with the linked file was a beneficiary or not. Linkage, however, produced another problem. The authors say that 78% of the survey records were linked. The authors say that they compensated with "a public-use weight that was adjusted to closely reproduce the corresponding public-use file population estimates by age." They did not say what proportion of the panel responded to all four waves of the panel; that non-response had to be compensated as well, but it is likely that the over-all response rate that

the article is based on is probably no higher than 65%. If the non-respondents are similar to the respondents and if those whose records are linked are similar to those whose records are not linked, the relatively low response rate is not a problem. If, however, the non-respondents are dissimilar to the respondents or those who did not furnish social security numbers for linkage are dissimilar to those who did, there may be a major bias in the linked data.

Most of the other items are there as a means of evaluating quality or because they are needed for meta-analysis. For example, the sample size and confidence interval are essential for meta-analysis that is, in effect, a method of combining studies. It is intuitively obvious that a large study with high response rates should have more weight than a small study with low response rates. Meta-analysis makes such considerations formal and makes it possible to produce a composite estimate from all the studies.

A study based on personal interviews in people's homes is, if done well, of higher quality than a telephone survey especially when medical conditions and income are items of interest because there is an association between income and telephone ownership and between disability and telephone ownership. However, one cannot conduct a meta-analysis of one study. It must stand alone with its strengths, which are considerable, and its weaknesses, which have been mentioned. One of the greatest strengths is the demonstration of how difficult it is to model the disability determination process, something that could be done only by people involved in the process.

One local study

The assignment was to find studies that provided national estimates of the number of people eligible for disability benefits who were still working. There is one local study that cannot provide national estimates, but does suggest other resources that SSA might investigate.

Brehm and Rush (7) arranged for disability assessments of the data from the first 17 examinations of the Framingham Heart Study. There are a number of benefits of this study that might be carried to other longitudinal studies. One is that there is a comparison between the self-identified disabled and the objective impaired. The major finding was that the disabled, but not the impaired, were more likely to be low education. That is, there was a difference in level of education between the disabled and non-disabled, but there was no difference between the impaired and non-impaired. A second finding is that it was possible to look at employment by impairment status but, more important, there was a possibility of seeing how the developing impairment translates into disability. For example, of the men ages 54 years and below who met or equaled the SSDI impairment listings, 96.9% were employed one examination before impairment, 90.7% at the examination where they were rated as impaired, 60.0% one examination after impairment, and 48.8% two examinations after the impairment.

Footnotes

1. 42 U.S.C. § 12102(2); see also 29 C.F.R. § 1630.2(g).
2. Katz, S. et al. (1963). Studies of illness in the aged: The index of ADL, A standardized measure of biological and physiological function. *Journal of the American Medical Association*, 185, 914-919.
3. SSA website - www.ssa.gov
4. Keller, D. M., Kovar, M. G, Jobe, J. B., & Branch, L.G. (1993). Problems eliciting elders' reports of functional status. *Journal of Aging and Health*, 5(3), 306-318.
5. Kovar, M G., Lee, L., Hess, H., & Arday, S. (2001). *Cognitive testing of a questionnaire for a dual-mode survey of Medicare beneficiaries*. Proceedings of the Survey Research Section, American Statistical Association, Alexandria VA.
6. Rodgers, W. L., & Miller, B. (1997). A comparative analysis of ADL questions in surveys of older people. *The Journal of Gerontology: Social Sciences*, 52B (Special Issue), 21-36.
7. Brehm, H. P, & Rush, T. V. (1988). Disability analysis of longitudinal health data: Policy implications for Social Security Disability Insurance. *Journal of Aging Studies* 2(4), 379-399.

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Summary of Studies Reviewed

Title	Age	Gender	Source of Income	Severity Measure	Sample Size	Response Rate	Confidence Interval	Data Source	Year of Data Collection	Mode of Data Collection
Burns	18-65	M/F			997			NRH	1989	Mail
Rubin	<65	M/F						SIPP	1984	In-person & Phone
LaPlante, 1997	<65	M/F			116,929			NHIS	1989	In-Person
LaPlante, 1996	<65	M/F			21,500 HHs			SIPP	1990	In-person & Phone
LaPlante, 1991	18-69+	M/F			390,000			NHIS	1983-1986	In-person
LaPlante		M/F			108,815			NHIS	1990	In-person
Sebesta	15-78	M/F			1,949			ACSUS	1991-1992	Telephone
Ireys	20-24	M/F			421			CSHCN		Telephone
Hurwitz	25-64	M/F			117,000			NHIS	1989	In-person
Mayfield	25+	M/F			21,907			NMES	1987	
DeRoos	18-64	M/F			1,416					Mail
Leigh		M/F						BLS/SDS	1985 & 1986	Record Review
LaPlante	15+	M/F						Census CPS,NHIS	1980/1990, 1990	In-person & Phone,
Shwartz		M/F		**	5,664			MGCD	1992	Record Review
MacKenzie	18-64	M/F			312					Patient Interview
Adler, 1990		M/F			20,000 HHs			SIPP	1984	In-person & Phone
Adler, 1995		M/F			21,500 Hhs			SIPP	1990	In-person & Phone
Muller		M/F			33,755			SSR	1976-1988	Record

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								SSA CWHS		Review
Schechter, 1999		M/F			8,188			NBS & NBF	1982 & 1992	Interview
Hennessey		M/F			1,003			NBF	1992	Interview
Schechter, 1997		M/F			8,188			NBS & NBF	1982 & 1992	Interview
Muller		M/F			4,453			NBS	1982	Interview
Dwyer	18-64	M/F	Linked to SSA records	Yes	25,525			SIPP	1980	In-person, Phone, & Records

** There is a very-detailed table in the paper on the levels of severity, but they do not map into the SSA definition.

Acronyms

ACSUS	AIDS Cost and Services Utilization Survey
BLS/SDS	Bureau of Labor Statistics/Supplemental Data System
CPS	Current Population Survey
CSHCN	Children with Special Health Care Needs
MGCB	Media Group Comparative Database
NBF	New Beneficiary Follow-up Survey
NBS	New Beneficiary Survey
NHIS	National Health Interview Survey
NMES	National Medical Expenditure Survey
NRH	National Rehabilitation Hospital (NRH) Survey of Working-Age Persons with Severe Physical Disabilities
SIPP	Survey of Income and Program Participation
SSR	Supplemental Security Record
SSA	Social Security Administration
CWHS	Continuous Work History Sample

Phase II Review of Existing Datasets

Results in Brief

There are eight surveys with questions on disability that can be used to produce national estimates. Two are telephone surveys; one of those is a one-time survey; the other is a repeated cross-sectional survey. Of the six in-person surveys, one is a repeated cross-sectional survey, two are panel surveys, and three are longitudinal.

Four of the in-person surveys have the information needed to estimate the number of medically eligible non-beneficiaries, although one survey does not span the entire age range. The National Health Interview Survey Disability Supplement (NHIS-D), the Survey of Income and Program Participation (SIPP), and the Medical Expenditure Panel Survey (MEPS) include all adults; the Health and Retirement Survey (HRS) began with people ages 51-62. Three of the surveys--the SIPP, the HRS, and the NHIS-D have the added advantage of linkage to Social Security Administration (SSA) records.

Introduction

Dwyer and colleagues (Dwyer et al., 2001) demonstrated that it is possible to use survey data to estimate the number of people who are medically eligible for SSDI or SSI but who are not beneficiaries. More important, they were able to validate the survey estimates with the SSA because the 1990 panel of the Survey of Income and Program Participation (SIPP) was linked to SSA records. That is, they knew who was receiving benefits because of the linkage. They did not have to rely on survey responses for that. They did, however, have to rely on survey responses for medical eligibility.

The Dwyer paper was the culmination of work by SSA staff that was designed to model the disability determination process. For that they needed the matched SSA application records. It is not so certain that matched records are essential for estimating the number of eligible non-beneficiaries. There are well-known disadvantages of relying on respondents for information about whether they are on SSDI, but there are also disadvantages to using the linked records.

There are other surveys that could be used to make such estimates--as could later panels of the SIPP. By searching for surveys that included questions on disability, we located eight surveys. Four have large sample sizes and the requisite questions on disability and sources of income. Three are also linked to records of the Social Security Administration. They are:

Survey of Income and Program Participation (SIPP)
National Health Interview Survey Disability Supplement (NHIS-D)
Health and Retirement Survey (HRS)

Methodology

There are no databases of surveys as there are of publications, but we followed the same strategy. We cast the web as widely as possible on the assumption that we could eliminate surveys that did not meet our evaluation criteria. Therefore, we obtained the questionnaire for any survey that asked questions on disability. We then used more discriminating criteria to evaluate the surveys. These criteria were similar to those used for the published studies but were more flexible because we could review the questionnaire to determine whether something was possible.

Criteria for Evaluating the Surveys

Questionnaire

Age	Mandatory - SSI requires that one meet the age qualification to receive SSDI benefits. Therefore we are only interested in those who meet the age requirement of 18-64 years of age.
Source of Income	Mandatory – Whether the individual is receiving SSI or SSDI benefits must be known, as well as whether the individual is earning income.
Amount of Income	Mandatory - Individual must meet the “amount of earned income” eligibility criteria. This amount changes over time. It is important to distinguish between family income and individual income. Only individual earned income determines eligibility for SSI and SSDI.
Disability	Mandatory – This identifies those who are disabled.
Severity	SSA definition is that the disability must be of 12 or more months duration or will result in death, must prevent gainful employment, and it is preferable that the disability be due to a condition that is on the medical listing. If the study has any measure of severity, we noted it and recorded the questions.
Condition	If the applicant has a severe impairment that is caused by a condition that is on the medical listing, he or she is granted benefits at stage three of the process. That negates the necessity for demonstrating capacity for past work, or for other work (the applicant has already

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demonstrated lack of capacity for being gainfully employed at present).

Capacity for Work Mandatory only if applicant goes on to stages four and five.

Gender Not Mandatory – Gender identification is not necessary for inclusion but might be useful for review and discussion/comparison.

Survey Sample Size Mandatory - Meta-analyses needs sample sizes to combine studies. It is also useful for deciding whether the study is large enough to contain enough individuals of interest, for example disabled persons not receiving SSDI benefits, to warrant analysis.

Response Rate Used in determining the quality of the study. Could lead to exclusion of certain studies from the analyses. The guideline for Federally-funded surveys cleared by the Office of Management and Budget is 80%.

Sample Design Must have the information on the design to make it possible to compute population estimates, confidence intervals, or standard deviations. Also useful for comparison among population groups or studies.

Year of Collection Legislative and other changes occur that impact eligibility requirements. Even the monthly amount used to determine whether the individual is gainfully employed is dependent on the year.

Mode of Collection As a general rule, a personal interview survey is of higher quality and can include more complex questions and question tools than surveys based on other modes. A telephone survey is usually higher quality with better response rates than a mail survey, but suffers from issues of non-coverage. A mail survey usually depends on simple questions and, in general, has the lowest response rates of the three. A combination of modes can be the optimal way to go. Web-based surveys were not an element in this review, being too new, and suffering from lack of coverage of a non-professional population.

Respondent The belief is that the best respondent is the individual of interest and that proxy respondents may give different answers than self-respondents. However, disability may prevent a self-response and to rely solely on self-response would eliminate many of the disabled.

Results

The eight national surveys with questions on disability are listed in the table along with an overview of the information that would be useful to estimate the number of medically eligible non-beneficiaries.

The first two surveys, the Behavior Risk Factor Surveillance System (BRFSS) and the NOD-Harris survey, are telephone surveys. Neither includes a question on the individual's income or source of income so it is impossible to know whether the individual is a beneficiary or not.

However, the BRFSS is designed to make state estimates so the SSA might be interested in investigating the possibility of adding questions. The BRFSS is a collaborative arrangement between the Centers for Disease Control and the states; it is actually 50 state surveys. The Center for Medicare and Medicaid Services (CMS) has negotiated directly with some states and added questions on older people. The SSA might add two questions: the question on the individual's income and whether any of that was received from SSA. The advantage of the BRFSS is that it is a very large survey that is designed for state estimates and the data are usually released within eight months of the end of the year. The disadvantage is that it is a telephone survey with low response rates in some states and there has been no research assessing whether people will answer those questions on a random-digit survey. It should be noted however, that there is an enormous amount of research evaluating people's responses to other questions on the BRFSS; the citations are on their website.

The other six surveys are personal-interview surveys. Two do not have the necessary questions on the questionnaire.

The Medicare Current Beneficiary Survey (MCBS) only has family income--it has neither the individual's income nor the source of the income. The survey is designed to learn more about the Medicare population with an oversample of persons under age 65. By definition those persons are disabled and should be on the SSA rolls and the survey is not useful for investigating the medically eligible who are not beneficiaries. It would be possible to do some methodological work on how well respondents report their enrollment. Because the sample is drawn from Medicare files, the social security numbers are present and correct.

The Current Population Survey (CPS) is actually an employment survey, not a health survey and so the disability questions are three questions about the individual's ability to work. There are no questions on severity of the disability or the causes. The Bureau of Labor Statistics (BLS) is conducting research to improve those questions, but they are not on the questionnaire yet. The CPS is conducted every month and has a supplement each month. SSA, if interested, could also investigate the possibility of adding a disability supplement. Note that the survey is a BLS survey, but the supplements are US Bureau of the Census supplements.

The other four surveys could be used to estimate the number of medically eligible non-beneficiaries and investigate their characteristics. They all have large samples, extensive questions on disability, batteries of questions on income including source of income, and three of them are linked to SSA records.

Probably the best source is The National Health Interview Survey (NHIS). It is a very large survey (about 800 households a week) with the unique feature of being in the field every week to avoid seasonal effects. The basic questionnaire is fixed, changing only once a decade or so, but every year there are supplements. In 1994-95 there were two supplements of special interest - a Disability Supplement and a Family Resources Supplement. The Disability Supplement was designed to meet the needs of a number of agencies including the Office of Research and Statistics and SSA. The NHIS-D allows analysts from varying programs to combine the data in different ways to meet specific agency or program needs. It also includes questions on the condition causing each disability. The Family Resources Supplement has questions on jobs, earnings, and program participation, including disability benefits. Therefore, it is possible to estimate the number of medically eligible non-beneficiaries and describe them from the questionnaire alone, but it is not necessary. All of the records from the NHIS from 1994 through 1998 are being linked with the Social Security records. The linkage is not finished yet, but it is underway.

The Medical Expenditure Panel Survey (MEPS) is based on the NHIS sample, so it has all of the NHIS data (except the follow-up supplement) in addition to the expenditure data. The sample is smaller, about 42,000 persons a year, but it is still a large survey. In addition to the household survey MEPS has a nursing home survey. That is a major advantage for studies of disability because a large proportion of the most-disabled population is in a nursing home.

The Health and Retirement Survey (HRS) was begun to address a major need. There were excellent economic surveys and excellent health surveys but there was no survey that did both when it was designed over a decade ago. The questions on disability and on income are excellent and it also is linked to SSA records. An advantage is that it is a longitudinal survey; people are interviewed every two years. The disadvantage is that it does not cover the entire age range. Because the intent was to study the economic and health correlates of retirement decisions (and because it is funded by the National Institute on Aging) the ages at the beginning of the study were 51-62. However, the committee that recommended that NIA should fund a major longitudinal data collection said that it should focus initially on retirement decisions, and that the design of the study recognize the important roles played by: pension and Social Security retirement incentives; the match of physical and cognitive job demands and worker capacities; health and longevity; family responsibilities and husband/wife career choices; economic status; and housing and location choices. It was definitely designed with SSA in mind. Also, according to the Dwyer, et al. (2001), 35% of the medically eligible non-beneficiaries were 55-64 years old, so the HRS will include a significant portion of the population of interest. The sample is smaller than the sample for the other surveys but it is a large sample of the restricted age range.

The one survey that has been used to study this question may not be the most useful. The Survey of Income and Program Participation (SIPP) is really what its name says. It is a survey of income and its relation to participation in public programs. Because health influences participation, there are quite a few health questions but they do not map well into the SSA definition.

An advantage of the HRS and the SIPP is that they are longitudinal surveys. In the HRS people are interviewed every other year for many years; in the SIPP they are interviewed every four months for 2.5 years. It would be possible from either survey to follow the changes in the lives of people who were on the program and compare them with the lives of people who were not. It would be possible, for example, to discover whether the people on SSI or SSDI did indeed die or remain disabled.

Finally, there is a caveat. The surveys need to publicize that they are linking the data and develop standard means of access. The HRS is very open; the information is on the website and means of access are laid out. The SIPP linkage has been going on for about a decade. The US Bureau of the Census certainly has a policy on access, but it could not be found on the website. The NHIS linkage is not yet completed. The National Center for Health Statistics has developed a policy but it is not easy to find.

Discussion

Although we could find only one paper that addressed the issue of how many people who are medically qualified for SSI or SSDI are not beneficiaries, we found four large national surveys that could be used to address the question. One is the SIPP, which was the source of the data used in the Dwyer paper, but the other three have not been used and they have some advantages over the SIPP in that they have more extensive questions on health and disability.

There might be some reason to use all four surveys to make the estimate. It would help bracket the estimate. The questions to define disability are different on every survey. We would have more confidence in the estimate if two surveys produced a number within sampling error of one another.

At this point we do not have a recommendation on whether to use the linked data for national estimates or not. The only paper we have seen (Olson, 1999) on the success of linking is on linking to the HRS. The HRS, unlike the SIPP and the NHIS, required that people sign the consent forms to have their data linked. However, if they did not get a good number the first time, they tried again at the two subsequent interviews. Despite three efforts, the linkage rates were 75%. Olson reports that result as encouraging because, she wrote, "SSN reporting has been in the 70-74% range in the early 1990s in the Survey of Income and Program Participation (SIPP) conducted by the Bureau of the Census," and "in March 1998, the CPS reporting rate for respondents age 15 and over was only 56%." (CPS has one respondent reporting for the entire household). The linkage with the NHIS-D is likely to be lower than either SIPP or HRS because the NHIS made only one

attempt to obtain the number and because in the mid-nineties the NHIS still had one adult reporting for all other members of the family who were not present.

A 75% linkage rate is not encouraging as that means that the effective response rate for a linked file is probably about 60% assuming a survey response rate of 80% $[(0.75)(0.80)=0.60]$. Both SIPP and HRS produce files with data weighted both for survey non-response and for non-linkage so it is possible to produce population estimates from either survey using the linked data. However, we do not feel that there has been sufficient research to say that the linked data are better than the personal reporting for estimating the number (or characteristics) of medically-eligible non-beneficiaries. We do not know whether those who furnish SSNs are different from those who do not. We can envision, for example, that people receiving benefits might be less likely to reveal their SSN for matching than people not receiving benefits, which could occur if respondents felt that their records would be subject to review. The problem is that we do not know.

We first recommend research on comparing data on respondents whose information was linked with those whose information was not linked. Questions, such as whether linkage rates were higher or lower for people who reported receiving benefits, need to be answered before policy is based on analyses. Second, results of those analyses should be used in weighting the linked files for national estimates. The files are weighted for non-response and are also weighted for non-linking. But that weighting can be improved if knowledge about those whose files did not link is included. Finally, we recommend research on the estimation. Dwyer and her colleagues (2001) demonstrated that varying the assumptions produced a wide range of estimates. That sort of careful work needs to be replicated for the other surveys. The issue is important. SSA needs to set up a continuing research project with the goal of having a standard set of questions that can be added to the longitudinal or repeated cross-sectional surveys of the Federal government.

Second, we recommend that the data set created for the study based on the 1990 panel of SIPP be investigated for characteristics of the medically-eligible non-beneficiaries--both those who were gainfully employed and those who were not, and that that study be replicated using data from a later large SIPP panel. Since the SIPP is repeated, the work can be repeated with every large panel (or by combining two smaller ones) and SSA will have a tool for continuous monitoring.

Third, the NHIS-D should be investigated for a similar analysis. That survey was actually designed with SSA needs in mind as it was designed under supervision of the Office of the Assistant Secretary for Planning and Evaluation (ASPE) when SSA was still part of the Department of Health and Human Services.

Finally, we recommend that SSA collaborate with other Federal agencies to get surveys that are needed and to get questions suitable for SSA onto ongoing surveys. There are, for example, no surveys of employers to learn of their accommodation to the needs of disabled workers. Surveys of employers are a function of the Department of Labor; SSA might be able to work with Labor to get such surveys underway. Labor, through the Bureau of Labor Statistics (BLS) is already

designing questions for the Current Population Survey (CPS) to measure the employment rate of disabled persons. The definition of disability to be used for that survey is not the SSA definition; it is the Americans with Disabilities Act (ADA) definition, but the two agencies could work together to learn how well the two definitions map into one another. The National Center for Health Statistics is considering another Disability Supplement to the NHIS a decade after the first one. SSA should be working with them to make certain that the SSA questions are on that questionnaire.

To conclude, no household survey can replicate the disability determination process precisely. But if the SSA experts who know the process, and especially the essential elements of the process, work with the people who conduct the large national surveys, the SSA could have a good system for monitoring the flow of medically-eligible disabled persons. It may be less possible to build a monitoring system for the work history needed to determine SSDI eligibility because survey research has demonstrated that people with complex work histories do not remember the details. But SSA could also investigate whether it is reasonable to obtain what the agency needs.

Citations for Studies Reviewed

- Dwyer, D., Hu, J., Vaughan, D. R., & Wixon, B. (2001). Counting the disabled: Using survey self-reports to estimate medical eligibility for Social Security's disability programs. *ORES Working Paper Series, Number 90*.
- Olson, J. (1999). Linkages of data from social security administrative records in the health and retirement survey. *Social Security Bulletin, 62(2)*, 73-85.

Surveys that Can be Used to Make National Estimates of the Number of Persons with Disability

Name of Survey	Sample Size	Year	Type of Survey	Income	Age
Telephone					
BRFSS	189,450 in 2000	1984-present	Repeated Cross-sectional	Family	18+
NOD Harris	2,136	1994	One-time	Family	16+
In-Person					
NHIS	45,000 HH per year	1957-present	Repeated Cross-sectional	All sources Individual Linked	All ages
NHIS-D	25,805	1994-95		All sources Linked	18+
CPS	50,000 HH	1940- present	Panel	Earned	15+
March	72,000	Annual		All sources	
MEPS	42,000	1977-present	Panel	All sources	All ages
HRS	12,600 in 1992	1992	Longitudinal	All sources Linked	51-62 at start
SIPP	20,000 HH	1988- present	Longitudinal	All sources	15+
SIPP-D		Cyclic		All sources Linked	15+
MCBS	16,000	1991-present	Longitudinal	Family	Medicare beneficiaries

Acronyms

BRFSS	Behavior Risk Factor Surveillance System
NOD Harris	National Organization on Disability and Harris
NHIS	National Health Interview Survey (and NHIS-D, Disability Supplement)
CPS	Current Population Survey
MEPS	Medical Expenditure Panel Survey
HRS	Health and Retirement Survey
SIPP	Survey of Income and Program Participation (and Disability Supplement)
MCBS	Medicare Current Beneficiary Survey

Recommendations to the Social Security Administration

The Social Security Administration (SSA) has a wealth of resources and knowledge, but an unfortunate separation from other agencies in the Federal government with stronger research commitments.

Our first general recommendation is to build on the research capability that SSA already has. Authors or co-authors of the two useful papers, that by Dwyer et al. and that by Brehm and Rush, are at SSA. Continuation of their work is highly recommended. The paper by Dwyer et al. was based on the 1990 cohort of SIPP, but SIPP is a continuing survey with an especially large cohort after the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 was passed. That work, with the additional step of estimating the proportion or number of those people who work, should be ongoing. In the same fashion, there are other longitudinal studies with repeated examinations that could be subject to the same analysis as Brehm and Rush gave Framingham. One of the comments in that paper was that there were too few blacks for a racial analysis; there are longitudinal surveys in the South that are based primarily on black people. The analysis should be repeated for other studies. Finally, SSA was one of the co-funders of the 1994 Supplement on Disability to the National Health Interview Survey (NHIS-D), which had questions specifically designed to act as a proxy for the SSA disability. To our knowledge, nothing has been published from that. Analysis and publication of the SSA-specific data from that survey is long overdue.

There is basic research capability at SSA. Our second recommendation is that it be expanded either by increasing staff or by reliance on the DRI, and that a long-term research agenda be established. The short-term agenda might be to conduct the research on the quality of the existing survey data, especially the files that are linked with SSA files, and the long-term agenda might be to develop modules that can be added to other national surveys, especially the panel or repeated-cross-sectional surveys.

The immediate short-term research needs are many and obvious. Without trying to develop a comprehensive list, I would suggest research on the difference between examination-based and self-reported impairment or disability (there is also a need to standardize the use of those words, but that is a different subject and has already, to its own satisfaction, been done by the World Health Organization). Brehm and Rush showed how this could be done on the Framingham study. The possibility of replication on national surveys such as the NHANES should be investigated and funded if feasible. I would also suggest methodological work on the possible biases of the linked files. We have done the research on potential biases in responses, and try to weight for those. But, to our knowledge, no one has done the research on the potential biases in the linkages, and that needs to be done. The potential for bias is large for two reasons; the effective sample is often small and the differences between those whose records link and those whose records do not may be large. When the response rate and the linkage rate are multiplied, the effective sample is sometimes no more than 60% of even the best sample. It is entirely possible that those who have no fears of the linkage are more likely to supply the linkage information than those who do have

something to worry about.

The long-term research could be based on improved working relations with other agencies. The Bureau of Labor Statistics is developing a module to estimate the prevalence of disability that will be administered as part of the in-person interview. There has been a great deal of research on that module, but to our knowledge there has been no input from SSA. It is probably too late now for that survey; it is not too late for other surveys. A first step might be working with other agencies to develop appropriate questions on disability. When the questions on how to ask for self-reports of disability have been developed, those questions can be added (by paying for the cost) to other national surveys such as the NHIS and the NHANES. Another example of working with other agencies might be to investigate how the definition of the Americans with Disabilities Act (which is being used by BLS for the CPS) and the ICF (the International Classification of Functioning, Disability and Health used by the NCHS surveys and recommended for all health data collection) and the definition used by SSA relate to one another. It is possible that a means for reconciling these can be found; if it is not, their differences must be quantified so that SSA is not caught short by headlines such as “There are xxx million disabled people in this country” without any notion of how that translates into SSA policy.

There is a major need for research on how to measure disability in the working-age population. There have been half a dozen surveys of the “elderly” in the past twenty years--many of them longitudinal. There has been a great deal of research on how to measure “disability” in the population age 65 and older in surveys. There have been no surveys focused on the working-age population (the HRS focuses on the upper end) and there has been, as far as I know, no research on how to measure disability in the working-age population. The National Institute on Aging funds the research on the population age 65 and older. It is SSA’s responsibility to fund the research on the working age population--or to investigate other ways in which this work might be done.