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CHARACTERISTICS OF PERSONS WITH DEVELOPMENTAL DISABILITIES:

EVIDENCE FROM THE SURVEY OF INCOME AND PROGRAM PARTICIPATION

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As Federal and state programs affecting persons with developmental disabilities have been reevaluated in the last twenty years there has been a rapid growth in the demand for information about these persons. Unfortunately, little comprehensive information has been available about the general characteristics of this group. As a result, many of the new interventions had to be developed without basic information about the number, demographics, functioning, economic status, and overall health of persons with developmental disabilities, particularly those persons living in the community rather than in institutions.

Information from the Survey of Income and Program Participation (SIPP) can be used to address this paucity of information about persons with developmental disabilities.[1] SIPP is a nationally-representative survey that collected data about the characteristics of noninstitutionalized persons, including information about basic demographics, income, work, use of government programs, and general health and disability. While it is not possible to identify precisely persons with developmental disabilities in SIPP, the available information can be used to develop a profile of persons who are likely to have developmental disabilities. This population profile provides valuable insight into the general nature of this group.

The first section of this profile provides an overview of SIPP. The second section examines the definition of developmental disabilities and the ways in which the information

[1]The U.S. Bureau of the Census (1986) and Mathematica Policy Research (1989) present SIPP-based profiles of persons with disabilities and impairments in general. Additional information about the implementation of SIPP and the types of data collected is presented in U.S. Bureau of the Census (1987).

collected in SIPP can be used to approximate this definition. The third section then provides information about the number and characteristics of persons who are identified as being likely to have developmental disabilities.

OVERVIEW OF THE SURVEY OF INCOME AND PROGRAM PARTICIPATION

The Survey of Income and Program Participation is a nationally representative longitudinal survey of the adult civilian noninstitutionalized population in the United States. This survey collects detailed monthly information on income, program participation, and wealth. It is a multi-panel longitudinal survey to which replacement panels are added each year. The first (or 1984) Panel began in October 1983 and interviewed a longitudinal sample of persons at four-month intervals for a period of two and one-half years. The SIPP sample is defined by adults, age 15 or older, residing in approximately 20,000 addresses (dwelling units) forming a cross-section sample of dwelling units in the United States. Although the survey is longitudinal, it is designed to support cross-sectional estimation for persons, families, and households residing in the 50 states and the District of Columbia.

Each round of interviewing (or wave) asks a standard "core" set of questions about income, employment, and participation in several government programs. Most waves also include topical modules that ask supplemental questions pertaining to a variety of issues that vary from interview to interview. One topical module in the 1984 Panel collected information about health conditions and limitations in functioning and work. It is this module from which this profile of persons with developmental disabilities has been developed.[2]

[2]Specifically, data are drawn from Wave 3 of the 1984 panel supplemented with information from Waves 1, 2, and 4 and with edited data developed by the Social Security Administration (Vaughan, 1989). The integration of data from other waves and from the Social Security Administration was necessary to supplement the Wave 3 information about beneficiary status for

Estimates of persons with developmental disabilities presented in this paper reflect the population in April 1984. The population estimates pertain to the U.S. civilian noninstitutional population, which comprises about 98 percent of the total U.S. population. The estimates are based on sample weights that reflect the probability of selection into the sample and adjustments to account for interview nonresponse and to reflect independent estimates of persons by age, race, and sex

Because these estimates are derived from a sample survey, they are subject to sampling and nonsampling error. Sampling error stems from the natural variation of characteristics in the population and the fact that only a sample of the population is interviewed. Sampling error is explicitly taken into account when presenting estimates and making comparisons. Estimates where the standard error is more than 30 percent of the estimates's value are explicitly marked in the table. Furthermore, all comparisons discussed in the paper have been found to be statistically significant at the 90 percent level using a two-tailed test; other differences may not be significant. Formulas for approximating standard errors and making statistical tests are presented in U.S. Bureau of the Census (1987) and in Bye and Gallicchio (1988). In reporting estimates, all population counts have bee rounded off to the nearest 1,000 persons. Estimates of percentages are computed on the unrounded numbers, but are reported rounded to one decimal place.

Nonsampling error cannot be explicitly measured or completely eliminated. Examples of nonsampling errors which affect the estimates presented here include:

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recipients of Social Security benefits in order to identify those persons who were receiving benefits because they were disabled rather than because they were retired or were survivors or dependents.

- Misreporting of key variables used to classify persons as developmentally disabled, particularly the variables pertaining to limitations in work and the age at which such limitations became manifest.

- Noninterviews which although they are corrected in part by the weighting process may still result in some bias because sample attrition in SIPP is not random.
- Item nonresponse and inconsistencies across responses which are corrected in part by the edit and imputation procedures employed by the Census Bureau in producing the data. However, these procedures do not always perform well, particularly at the extremes of the income distribution.

For a more complete discussion of sampling and nonsampling error in SIPP see U.S. Bureau of the Census (1987) and the references noted therein.

DEFINING DEVELOPMENTAL DISABILITIES WITH DATA FROM SIPP

The distinguishing feature of developmental disabilities is that they become manifest during childhood and severely interfere with the typical course_ of a person's development. Initially, the term developmental disabilities was used to refer to persons with mental retardation, cerebral palsy, epilepsy, and autism. Since the late 1970s, the focus of the definition of developmental disabilities has shifted away from lists of specific conditions and now emphasizes limitations in specific life activities and individuals' needs to deal with these limitations. Developmental disabilities are currently defined by the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987 as: a severe, chronic condition that:

1. is attributable to a mental or physical impairment or a combination of mental or physical impairments

2. is manifested before the person attains age twenty-two

3. is likely to continue indefinitely

4. results in substantial functional limitations in three or more of the following areas of major life activity:

- o self-care
- o receptive and expressive language
- 0 learning
- o mobility
- o self-direction
- o capacity for independent living
- 0 economic self-sufficiency

5. reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment or other services which are of lifelong or extended duration and are individually planned or coordinated.

SIPP does not contain sufficient information to operationalize this complete definition, even if it were clear what this definition meant by a "substantial" functional limitation or how to determine a need for lifelong interdisciplinary services. Thus, it is necessary to approximate this definition using the information available in SIPP, paying particular attention to approximating two critical aspects of the definition: the severity of the limitation and onset prior to adulthood.

1. Measures of the Severity of Limitations

For persons ages 16 to 72, SIPP contains information about severe limitations in four of the seven major life areas listed in the definition of developmental disabilities: economic self-sufficiency, self-care, independent living, and mobility. Limitations in economic self-sufficiency are measured by questions that ask whether the person's health or condition either (1) prevents them from working or (2) limits the amount or kind of work that he or she can do.[3] Limitations in self-care can be inferred from questions that ask about the need for assistance with basic Activities of Daily Living (ADLs): eating, dressing, personal hygiene, getting in and out of bed,

[3]Persons who have worked at any time in the last four months are not asked about whether they are prevented from working. Thus, persons who have recently attempted to work and failed or who have worked in supported settings will only be asked about work limitations not whether they are prevented from working.

and ambulation in the home.[4] Limitations in the ability to live independently are measured by questions that ask about the need for assistance with some of the activities typically included in lists of Instrumental Activities of Daily Living (IADLs), specifically light housework, meal preparation, and getting around outside the house.[5] Mobility is assessed in questions about difficulty climbing stairs or walking three blocks.

This information about limitations in work and the need for assistance with ADLs or IADLs provides a good basis for identifying persons with severe limitations. However, there are two important weaknesses with this information. First, SIPP addresses only four of the seven life areas contained in the definition of developmental disabilities. This focus means that some individuals with severe limitations in self-direction, communication, or learning may be missed by a classification scheme using only the data in SIPP. Second, SIPP does not explicitly distinguish between limitations that are expected to persist indefinitely and short-term limitations. Thus, persons with temporary limitations related to illnesses, accidents, or childbirth may be classified in the same manner as persons with chronic limitations related to mental retardation or cerebral palsy.

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[4]Katz et al. (1963), Lawton (1970), and Phillips, Baxter, and Stephens (1981) discuss how the need for assistance with ADL indicates a meaningful limitation in a person's ability to care for him/herself.

[5]Other activities commonly included on lists of Instrumental Activities of Daily Living include shopping, using the telephone, traveling beyond walking distance, taking medications, and managing finances (see Phillips, Baxter and Stephens (1981). The specific IADLs included in SIPP appear to be oriented more toward physical activities than are some of the excluded IADLs such as the need for assistance with shopping, using the telephone, and money management. Thus, the data available in SIPP may miss persons whose ability to live independently is limited due to cognitive rather than physical limitations.

For children, both the practical definition of developmental disabilities and the information collected in SIPP are different than for adults. Many of the life areas are ill-defined or do not pertain to children, particularly the life areas of economic self-sufficiency, self-direction, and independent living. Thus, a simpler definition based on typical activities for children would be appropriate. SIPP essentially uses such a modified approach by collecting information about whether a child (age 17 or younger):

- Has a long-lasting physical condition that limits his or her ability to walk, run, or play
- Has a long-lasting mental or emotional problem that limits his or her ability to learn and do regular school work

While there are undoubtedly some measurement problems with respect to these questions, children with limitations in either of these two areas are likely to be developmentally disabled.[6]

2. Measures of the Onset of Limitations

SIPP collects information about the onset of limitations only in relation to work For persons who report being limited in the amount or type of work that they can do, SIPP determines whether the limitation began before the person became of "working-age." For persons who report being unable to work, SIPP determines whether they have ever been able to work While working-age is not explicitly defined in SIPP, it seems to provide an acceptable

[6]Two types of measurement problems are likely to arise. First, parents may not be aware of developmental problems for very young children, particularly those children who have not entered school (at which time problems are more likely to be identified through school-based screening and testing efforts). Second, the SIPP questions do not provide an objective basis for respondents to determine how severe a limitation must be before it should be reported.

approximation to the aspect of the definition of developmental disabilities pertaining to onset prior to adulthood.

No age of onset is determined for limitations in ADLs or IADLs. However, for persons who report that their limitation(s) are due to mental retardation, it is reasonable to infer an onset during childhood. Children who are reported in SIPP as being limited in physical activities or learning have an onset prior to age 22 by definition.

3. Identifying Persons with Developmental Disabilities in SIPP

The information available in SIPP about persons ages 16 to 72 has been used to define three groups of persons that approximate to different degrees the population of persons with developmental disabilities:

- Narrow Definition classifies persons as being developmentally disabled if they report that their health or condition has always prevented them from working at a job or business.

- Middle Definition includes all persons who meet the narrow definition plus two other groups of persons:

  (1) those who report being currently unable to work and having a work limitation that started prior to working age

  (2) those who report having mental retardation and either needing assistance with ADLs or IADLs or receiving disability benefits.[7]

- Broad Definition includes all the persons who meet the narrow definition or who report a work limitation that began prior to their reaching working-age.

[7] SIPP collects information about conditions only in connection with reported limitations in work or the need for assistance with ADLs or IADLs. Disability benefits are those from the Supplemental Security Income (SSI) program, the Social Security Disability Insurance (SSDI) program, or Veterans Programs where the person has a disability rating of 100 percent.

The narrow definition includes persons with relatively severe limitations that arose prior to adulthood. Thus, persons meeting this definition are generally likely to be developmentally disabled The drawback of this definition is that it may exclude persons who have attempted to work despite their severe limitations or who have worked in supportive settings such as sheltered workshops or supported employment programs. Also, as noted earlier, persons with limitations in life areas other than work will be excluded from this definition.

The middle definition addresses these two deficiencies of the narrow definition by including persons with limitations due to mental retardation and persons whose work disability had its roots in limitations that arose prior to working-age. This middle definition is probably the most accurate of the three alternative SIPP-based definitions.

The broad definition is almost certainly over-inclusive since some persons who are limited in the amount or type of work they can do would not be impaired sufficiently to be considered to have a developmental disability. Nevertheless, this group provides a useful reference since it contains persons who have work limitations that arose prior to their reaching working-age.

In addition to these three groups, it is useful to consider those persons who would not be classified as developmentally disabled under any of the definitions. This group, which encompasses over 97 percent of the noninstitutional population ages 16 to 72, includes persons with no limitations in **functioning as well as persons whose** limitations arose in adulthood. This group provides a reference point for interpreting the information about persons with developmental disabilities.

These four groups are defined for persons ages 16 to 72, the persons who are asked the questions about work limitations. **It would also be possible** to define a fifth group: children

who are limited in their ability to walk, run, play, or learn. These children are profiled in Mathematica Policy Research (1989).

A PROFILE OF PERSONS WITH DEVELOPMENTAL DISABILITIES

Table 1 presents the characteristics of the groups identified by the three alternative definitions of developmental disabilities as well as the characteristics of the persons without developmental disabilities. As noted, the estimates in this table pertain to adults included in the SIPP sample who are between the ages of 16 and 72 years old.

The profile begins with an assessment of the accuracy of the SIPP-based definitions of developmental disabilities. It then turns to examine the demographic, economic, and health characteristics of the persons identified as developmentally disabled. The paper concludes with some general observations about using survey data to identify persons with developmental disabilities and about the information available in SIPP about this population.

1. The Accuracy of the SIPP-Based Definitions of Developmental Disabilities

There is no independent information with which to verify the SIPP-based classifications of persons as having or not having developmental disabilities. The classifications must therefore be judged on their consistency with other available information about persons with developmental disabilities. This can be done by comparing the prevalence rates implied by the SIPP data with rates estimated from other information. In addition, the severity of developmental disabilities should be reflected in the SIPP data about impairments and receipt of disability benefits.

The Prevalence of Developmental Disabilities. The prevalence estimates presented in the first two rows of Table 1 clearly indicate the differential inclusiveness of the three alternative

TABLE 1

PROFILE OF PERSONS WITH AND WITHOUT DEVELOPMENTAL DISABILITIES
AMONG THE NONINSTITUTIONAL POPULATIONS, AGES 16-72

April 1984

Population Characteristic	Persons Classified as Developmentally Disabled"			Persons Not Classified as Developmentally Disabled
	Narrow Definition	Middle Definition	Broad Definition	
Estimated Number of Persons (Thousands)	1,284	1,744	4,615	159,425
Estimated Prevalence (Percent of All Persons 16-72)	0.8%	1.1%	2.8%	97.2%
Limitations in Functioning: Percent of Group:[b]				
Needs Assistance with AOL or IADL[a]	35.8%	35.8%	14.6%	2.4%
Substantial Physical or Sensory Limitations'	23.2%	26.6%	23.3%	6.7%
Mild Physical or Sensory Limitation	16.8%	15.6%	19.0%	7.1%
No Limitations	24.3%	22.0%	43.1%	83.8%
Receipt of Disability Benefits (Persons 18-64 Years Old)'				
Receives Disability Benefits	61.8%	59.4%	24.4%	2.4%
Does Not Receive Disability Benefits	38.2%	40.6%	75.6%	97.6%
Percent of Group between Ages				
16-21 years	18.8%	15.8%	23.3%	13.8%
22-49 years	57.2%	57.8%	58.5%	57.7%
50-64 years	14.5%	16.5%	13.2%	20.3%
65-72 years	9.5%	9.9%	5.1%	8.3%
Gender: Percent of Group				
Male	38.9%	40.9%	51.6%	48.3%
Female	61.1%	59.1%	48.5%	51.7%
Race/Ethnicity: Percent of Group				
Black, Non-Hispanic	26.2%	23.6%	15.3%	10.8%
Hispanic	9.1%	8.2%	4.9%	5.4%
White, Non-Hispanic[d]	64.7%	68.2%	79.9%	83.9%
Education: Percent of Group with				
Less than High School	65.7%	61.9%	44.6%	26.7%
High School only	26.5%	27.8%	34.5%	37.8%
More than High School	7.8%	10.3%	20.9%	35.5%
Marital Status/Living Arrangements: Percent				
Married	17.9%	22.6%	33.5%	59.8%
Living with Spouse	9.8%	13.0%	13.9%	20.2%
Living with Spouse and Others	8.1%	9.7%	19.6%	39.6%
Not Married or Separated	82.0%	77.4%	66.6%	30.3%
Living Alone	11.0%	11.7%	11.1%	9.6%
Living with Relatives	68.5%	60.5%	50.8%	26.1%
Living with Non-Relatives	2.5%^^	5.2%	4.7%	4.6%
Household Economic Well-Being				
Mean Household Monthly Income	$1,462	$1,500	$1,951	$2,535
Median Household Monthly Income	$1.130	$1,135	$1,626	$2,108
Percent of Household Income from:				
Earnings	38.8%	38.0%	59.9%	74.5%
Social Security	23.4%	25.0%	13.3%	8.6%
Transfers	34.9%	32.5%	20.7%	6.7%

TABLE 1 (continued)

Population Characteristic	Persons Classified as Developmentally Disabled[a]			Persons Not Classified as Developmentally Disabled
	Narrow Definition	Middle Definition	Broad Definition	
Percent with Monthly Income'				
Below poverty level	32.9%	31.4%	21.2%	11.3%
Between 1 and 1.5 times the poverty level	16.3%	17.5%	12.8%	8.8%
Above 1.5 times the poverty level	50.8%	51.4%	66.0%	80.7%
Employment				
Percent Working in April 1984	NA	5.6%	42.0%	65.1%
Average Earnings for Persons who Work ($)	NA	$548	$935	$1,352
Percent Working who have Monthly Earnings Below $300	NA	58.0%	23.8%	13.2%
Health Measures				
Reported Health Status				
Excellent	6.4%^^	9.1%	12.3%	34.2%
Very Good	6.8%	7.8%	15.8%	27.8%
Good	29.1%	26.2%	31.9%	24.6%
Fair	35.0%	31.9%	28.3%	9.1%
Poor	22.8%	25.1%	11.7%	4.3%
Mean Number of Days in Hospital in Last 4 Months	1.3 days	I.7 days	0.9 days	0.32 days
Mean Number of Doctor Visits in Last 4 Months	3.1 visits	3.2 visits	2.6 visits	1.3 visits
Mean Number of Days Bedridden in Last 4 Months	9.9 days	11.4 days	6.2 days	2.1 days
Health Insurance Coverage: Percent				
Not Covered	11.3%	11.7%	18.8%	13.7%
With Private Coverage Only	21.0%	21.8%	46.1%	72.3%
With Private and Public Coverage	12.9%	14.4%	8.4%	7.4%
With Public Coverage Only	54.8%	52.1%	26.8%	7.5%
Percent with Mental Retardation	23.2%	27.4%	12.4%	NA
Sample Size	272	367	986	34,846

SOURCE: SIPP 1984 Panel, Wave 3 supplemented with data from Waves 1, 2, and 4.

[a]Three alternative definitions were used to identify persons with developmental disabilities. The "narrow" definition classifies persons as developmentally disabled if they report that their health or condition has always prevented them from working at a job or business. The "middle" definition adds to the narrow definition by also including (1) persons who report both being currently unable to work and having a work limitation that started prior to working age and (2) persons who report having mental retardation and a need for assistance with ADL or IADL tasks. The "broad" definition includes persons who are report a work limitation or being prevented from working where the limitation or inability began prior to working age.

[b]Appendix B provides a full definition of these categories.

'Receipt of disability benefits can only be determined for persons 18 to 64 years old.

[d]Other race/ethnicity groups are included with the white group.

[e]This poverty measure is based on the ratio of income in April 1984 to the monthly equivalent of the annual poverty threshold.

^^ This symbol indicates that the error of the estimate is greater than 30 percent of the value of the estimate.

definitions. The narrow definition classifies almost 1.3 million noninstitutionalized persons between the ages of 16 to 72 years old as having developmental disabilities. This estimate suggests a prevalence rate for developmental disabilities of approximately 0.8 percent of the adult noninstitutional population. The middle definition indicates that over 1.7 million adults (1.1 percent of the population group ages 16 to 72) would have developmental disabilities while the broad definition classifies 4.6 million such persons (2.8 percent of this age group) as developmentally disabled.

In order to compare these rates with those derived from other data sources, it is necessary to add in the persons with developmental disabilities who are excluded from SIPP. In particular, it is necessary to add in the estimated 250,000 persons who live in state and community-based facilities for persons with mental retardation and the approximately 80,000 persons with mental retardation who live in nursing homes.[8]

When these persons are added to the 1.7 million persons classified as developmentally disabled in the middle definition, the resulting total of just over 2 million adults implies a prevalence rate for adults of 1.3 percent. This rate is slightly below the prevalence rate of approximately 1.5 percent of the adult population (including persons in institutions) estimated by Kiernan and Bruininks (1986) on the basis of their review of the available prevalence literature. The prevalence rate corresponding to the narrow definition would be 1 percent while the rate corresponding to the broad definition would be 3 percent. Thus, the estimates based on SIPP appear to bracket the currently available prevalence estimates for developmental

[8]Lakin, et al. (1989) provides estimates of the number of persons with mental retardation in community-based facilities, while White, et al. (1987) provides an estimate of the number of such persons in state-operated facilities.

disabilities, with the middle definition coming closest to approximating the prevalence estimates derived from other studies. This consistency provides some reassurance that the SIPP-based classification identifies persons who are developmentally disabled. Of course, given the level of uncertainty inherent in the existing prevalence literature, it is unclear whether much importance should be attributed to the difference between the 1.3 percent prevalence rate estimated using SIPP data and the 1.5 rate suggested by the literature review of Kiernan and Bruininks.

The Extent of Impairments and Disability-Benefit Receipt Among Persons Classified as Having Developmental Disabilities. The sets of estimates following the prevalence estimates in Table 1 provide two alternative measures of disability.[9] The first is based on limitations in functioning and the second on receipt of benefits from programs targeted toward persons with disabilities. Because these measures of disability are based on some of the same variables as the classifications of developmental disabilities, some degree of correlation is expected. Nevertheless, these estimates suggest a consistency between the classification of developmental disabilities and other disability classifications. Furthermore, the estimates indicate the severity of impairments among persons classified as developmentally disabled.

For example, almost 36 percent of the persons identified by the narrow and middle definitions of developmental disabilities reported needing assistance with ADLs or IADLs. Another 25 percent reported having serious physical or sensory limitations. Less than 25 percent of the persons classified by these two definitions as having developmental disabilities reported

[9]These disability classifications were developed by Mathematica Policy Research (1989) in the process of developing a SIPP-based profile of all persons with impairments and disability. Appendix B provides a full definition of the categories and the specific SIPP variables used in their construction.

no need for assistance and no physical or sensory limitation. The corresponding figure for the general population without developmental disabilities is approximately 84 percent.[10]

Table 1 also indicates the extent to which persons receive disability benefits. Because information about receipt of disability benefits can only be obtained from SIPP for persons from 18 to 64 years old, the comparison of definitions of developmental disabilities and receipt of disability benefits is limited to persons in this age range.

SIPP data about the receipt of disability benefits is based, in part, on special procedures developed by the Social Security Administration (Vaughan, 1989). These procedures provide a means for using information in SIPP to determine whether Social Security beneficiaries under 65 years old are receiving benefits because of their own disability.[11] In addition, Supplemental Security Income recipients under 65 years old can be assumed to be receiving these benefits because of disability as can those recipients of Veterans' Administration (VA) benefits who report having a 100 percent VA disability rating.

The estimates in Table 1 show relatively high rates of disability-benefit receipt among persons identified in the SIPP as having developmental disabilities. Approximately 60 percent of the persons identified under the narrow and middle definitions are estimated to receive disability benefits. Not only does this indicate that many of these persons are sufficiently

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[10]It is interesting to speculate about the nature of the persons who meet the narrow definition (that is those who have always been prevented from working) yet have no need for assistance with ADLs or IADLs and report no physical or sensory limitations. One possibility is that these individuals have cognitive limitations that prevent them from working but are not captured by the impairment-related questions in SIPP that focus primarily on the ability to perform physical activities such as ambulating inside or outside the house, climbing stairs, and lifting.

"Beneficiaries who are older than 65 are paid out of the retirement trust fund and are considered as retired rather than disabled for Social Security purposes.

impaired to be considered disabled under the Social Security Administration's disability determination process, but it also indicates the relatively high use of public support by the persons classified as developmentally disabled.

Overall, these comparisons suggest that the SIPP-based definitions of developmental disabilities provide an imperfect but reasonable basis for identifying such persons. The high proportion of persons with limitations in functioning among those classified as developmentally disabled (particularly by the narrow and middle definitions) indicates the severity and multi-dimensionality of the limitations faced by persons in this group. The severity of the limitations is also indicated by the high fraction receiving disability benefits.

One disconcerting aspect of this comparison is that over 20 percent of the persons identified by the narrow definition report no need for ADL/IADL assistance or any sensory/physical impairments. It is unclear whether these are persons whose limitations are manifest only with respect to work or whether their limitations are not captured in SIPP. Given that the SIPP questions focus primarily on physical impairments, it seems likely that some persons whose limitations are primarily cognitive may not have reported being limited in SIPP. In the conclusion section we will return to the issue of the accuracy of the three definitions, after reviewing the estimated population characteristics.

2. Characteristics of the Persons Identified as Developmentally Disabled

All three of the alternative SIPP-based definitions of developmental disabilities identify, on average, persons who tend to have less education, earn less, live in poor households, and have poorer health relative to persons who are not developmentally disabled. In general, the characteristics of the groups identified by the narrow and middle definitions are similar, while

persons identified as developmentally disabled by the broad definition tend to have characteristics that would place them in between the groups defined by the other developmental disability definitions and the general population.

Demographics. The most striking findings with regard to basic demographics pertain to gender and race for persons classified using the narrow and middle definitions. In both these groups, approximately 60 percent are female while 52 percent of the non-developmentally disabled population is female. With respect to race, the fraction of Blacks among the persons identified by the narrow or middle definition is approximately 2.5 times the fraction for the general population. The broad definition also yields a higher than expected fraction of Blacks classified as developmentally disabled, although that definition did not produce a difference with respect to gender.

The reason for such differences is unclear. In part, it may reflect a combination of factors including the nature of the labor market and the focus of the narrow and middle definitions on being unable to work. If Blacks and women who become impaired at an early age perceive that there are few labor market opportunities, they may be more likely than other persons to drop completely out of the labor market. Given the overall patterns of earnings among groups defined by race and gender, such a perception might not be surprising. One implication of such a perception would be that Blacks and women would be more likely than similar persons in other groups to report in a survey that they were unable to work.[12] Correspondingly, Blacks and females would be more likely to be classified as developmentally

[12]Chirikos and Nestel (1981) and Parsons (1980) reports evidence of such tendencies among survey respondents: specifically, persons with poorer labor-market opportunities are more likely to report being disabled.

disabled under the narrow or middle definitions. Under the broad definition, which includes persons who are limited in work as well as being prevented from work, the distribution of men and women is essentially the same as the overall population, although there are still slightly more Blacks classified as developmentally disabled by the broad definition than would be expected on the basis of the overall population racial mix.

Clearly, these patterns warrant additional research into both the classification methods and possible explanatory factors. In addition, these patterns must be kept in mind when interpreting the other statistics in Table 1 since most of the other population characteristics examined are correlated with race and gender.

The information in Table 1 about education reflects the early onset of disability and the corresponding delays in educational attainment for persons with developmental disabilities. Two-thirds of the persons who meet the narrow definition of developmental disabilities did not complete high school compared with only a quarter of the general population. Similarly, fewer than 10 percent of the persons identified in the narrow and middle definitions have post-secondary education compared with about 35 percent of the non-developmentally disabled population.

The delay in development may also explain the observed differences with respect to living arrangement. We find that relatively few adults who are identified as having developmental disabilities are living independently, either by themselves or with a spouse. Most adults with developmental disabilities (almost 70 percent) are unmarried and living with relatives. In contrast, among the general population most adults are married and living with their spouse or are living alone. These findings are consistent with the limitations expressed in the formal definition of developmental disabilities.

Economic Status. The reliance on public support, which was seen in the fraction of persons receiving disability benefits, is also seen in the statistics pertaining to economic well-being. Persons identified as developmentally disabled under the narrow and middle definitions appear to live in households that receive over 55 percent of their cash income from Social Security or government transfer programs.[13] These households report receiving less than 40 percent of their income from earnings. In comparison, among the general population, households report receiving 75 percent of their cash income from earnings.

Despite the receipt of various types of income support, persons identified as having developmental disabilities tend to live in households that are substantially poorer than the general population. The average and median household income (in April 1984) for persons identified under the narrow and middle definitions was 40 to 45 percent less than for the general population. Among persons identified under these two definitions, approximately one-third live in poor households, three times the rate for the general population. An additional 16-17 percent of the developmentally disabled persons (identified with the narrow or middle definitions) are in near-poor households with incomes between 1 and 1.5 times the poverty level. When the poor and near poor groups are combined, almost half of the developmentally disabled persons are estimated to live in needy households. This raises concern about the ability of these households to meet the needs of persons with developmental disabilities.

Correlated with the observed low income of persons with developmental disabilities is a very low rate of employment. Less than 6 percent of the persons identified by the middle definition were working at the time of the interview compared with 65 percent of the general

[13]The income estimates reported in Table 1 include only cash income and exclude the value of food stamps, Medicaid, rent subsidies, and other forms of in-kind income.

population. Even when they work, the persons identified through the middle and broad definitions earn substantially less than workers in the general population.

Health Characteristics. The measures of health indicate that the narrow and middle definitions of developmental disabilities identify groups that have relatively poor health. Over half these persons report being in poor or fair health, with about 25 percent reporting that they are in poor health. In contrast, less than 15 percent of the general population report being in fair or poor health. Persons identified by the narrow and middle definitions also spend more days in the hospital, visit the doctor more often, and spend more time bedridden than the general population.

Due in large part to the coverage of Medicare and Medicaid, persons with developmental disabilities appear to be as able as the general population to obtain health insurance coverage. (The estimated fractions of persons without coverage classified under the narrow and middle definitions are not statistically different from the estimated fraction for the population as a whole.) Persons identified under the narrow and middle definitions, participate in the Medicare and Medicaid programs almost 5 times as much as do persons in the general population (two-thirds of the developmentally disabled groups have Medicare or Medicaid coverage compared with 14 percent of the general population). This differential rate of public coverage offsets the substantially lower rates of private health-insurance coverage among the persons identified as developmentally disabled.

It is interesting to note that among persons identified by the broad definition of developmentally disability, the fraction without health insurance is higher than among the overall population. Persons meeting the broad definition are, on average, less impaired than persons meeting the narrow or middle definitions, although persons meeting the broad definition may still

have substantial difficulties, particularly in obtaining and holding well-paying jobs. As a result, persons meeting the broad definition may fall in a gap between the major sources of health insurance: they are not covered by Medicare or Medicaid programs that would provide public coverage and yet they have too little employment, on average, to obtain private health insurance.

Another aspect of health pertains to the specific conditions that limit persons in work or other activities. SIPP collects information about the conditions that limit respondent's ability to work or perform basic activities (specifically, getting around and light housework/meal preparation). This condition information is potentially problematic because of misreporting of stigmatizing conditions. Marquis et al. (1981) found a large negative bias in reporting mental illness and it seems likely that there are similar problems with self-reports of mental retardation. Thus, it is likely that these types of stigmatizing conditions. are under-reported or misreported.

With this qualification in mind, it is interesting to note that only 23 to 27 percent of the persons classified as developmentally disabled under the narrow and middle definition indicate that their limitation is due to mental retardation. This rate is far below even the wide range of estimates reported in the literature, which indicate that between 35 and 90 percent of the developmentally disabled population is mentally retarded (U.S. Department of Health and Human Services, 1988). Thus, the finding in SIPP that fewer than 30 percent of the persons identified as developmentally disabled are mentally retarded suggests that there are problems with the classification scheme or the condition data. The number of persons reporting other conditions is generally too small to provide an adequate basis for precisely estimating the fraction of persons with other conditions.[14]

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[14]The estimate of no persons with mental retardation among the general non-developmentally disabled population reflects the way in which SIPP collects data about conditions. Only persons who report needing assistance with ADL or IADL activities or report

3. Conclusions from the Profile of Persons with Developmental Disabilities

Two general conclusions stem from the estimates reported in Table 1. One pertains to the use of survey data like that contained in SIPP to identify persons with developmental disabilities. The other is the poor economic and health condition of many of the persons identified as developmentally disabled in SIPP.

Using Survey Data to Identify Persons with Developmental Disabilities. No definitive assessment of the accuracy of survey-based identification of persons with developmental disabilities can be made without some sort of independent collaborative evidence. The SIPP-based classification suggests, however, that it is possible to use survey data to identify persons who are likely to have developmental disabilities. Prevalence rates derived from SIPP are generally consistent with the currently accepted prevalence rate estimates derived from other sources. In addition, persons identified in SIPP as having developmental disabilities generally have limitations in more than one area, a finding that is consistent with the multi-dimensional nature of developmental disabilities.

The challenge in identifying persons with developmental disabilities appears to be that definitions based on a single dimension may miss some persons who have severe limitations in other dimensions. Thus, the narrow definition, which is based only on an inability to work that originated prior to working age, identifies only about two-thirds of the number of persons expected to be developmentally disabled on the basis of independent prevalence estimates. In order to obtain a prevalence estimate that is consistent with those in the literature (e.g., the

being limited in work are asked about the conditions that create the limitation. Because persons who report mental retardation as a cause for one of these activities will be classified as developmentally disabled under one of the three alternative definitions, no persons reporting mental retardation will be included in the non-developmentally disabled population.

middle-definition rate), it is necessary to include persons identified as having limitations in other life areas such as self-care or independent living.

The inability to identify persons with developmental disabilities solely by asking about one life area reflects the complex nature of developmental disabilities. It may also reflect the results of formal and informal services which may enable persons with developmental disabilities to work or perform other basic functions despite their impairments. Thus, it seems that survey procedures to identify persons with developmental disabilities will need to ask about all or most of the life areas in the definition and possibly about specific conditions or support-service use.

The SIPP data also suggest that the administrative records of the SSI or SSDI programs would be an inadequate basis for identifying the general population of persons with developmental disabilities. Table 1 indicates that only 60 percent of the persons identified as having developmental disabilities in SIPP received disability benefits from these programs. While this estimated participation rate is not conclusive--due to the imprecision in identifying persons with developmental disabilities--the SIPP evidence does suggest that a sizable number of persons of interest to the developmental disabilities system may not be participating in the SSI or SSDI programs.

Characteristics of Persons with Developmental Disabilities. Beyond the methodological results of this profile lies the picture of a group who, on average, have limited economic resources with which to meet their needs. Compared with the general population, persons with developmental disabilities are less likely to hold a job, tend to earn less when employed, are more likely to live in poor households, and have poorer health. The relatively poor health status of persons with developmental disabilities (as shown in Table 1) coupled with expectations about the nature of developmental disabilities suggest that these are persons who need more than

average levels of service to meet basic living standards. However, the earnings and income findings indicate that these persons have less than average resources even when counting government income maintenance programs, although they appear to have an average level of access to health insurance as a result of the Medicare and Medicaid programs.

The general conclusion of this profile therefore reinforces the notion that efforts to assist persons with developmental disabilities cannot focus solely on specific health or physical conditions. These individuals and their families are likely to share traits common to other population groups that are poor or otherwise disadvantaged. Their problems are likely to reflect their low income, health concerns, living arrangements, educational attainment, and job prospects, just as much as the specific condition underlying their disability. Efforts to address this multi-dimensional problem must therefore be ready to address a range of issues and to function in the context of a group with high rates of poverty and low rates of employment.

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APPENDIX A

FACSIMILES OF THE 1984 SIPP THIRD WAVE QUESTIONS ON DISABILITY STATUS

(Reproduced from U.S. Bureau of the Census, 1986)

Port B — HEALTH AND DISABILITY

These next **few questions are** about. **..'s health.**	8334	1 ☐ Excellent 2 ☐ Very good 3 ☐ Good 4 ☐ Fair 5 ☐ Poor
1. Would you say **...'s** health in **general is** excellent, **very** good, good, fair, or poor?		
2a. Does . . . have any difficulty seeing words and letters in ordinary newspaper print even when wearing glasses or contact lenses if. . . usually wears them?	8336	1 ☐ Yes 2 ☐ *No — SKIP* to *Check Item T17*
b. Is.. . able to do this at all?	8338	1 ☐ Yes 2 ☐ No
CHECK ITEM T17 is . . a self-respondent?	8340	1 ☐ Yes — Mark *2c* through *2e by* observation 2 ☐ No — ASK *2c* through 2e
2c. Does . . . have any difficulty **hearing** what is said in a normal **conversation** with another parson? (Using a haaring aid if. . . usually wears one.)	8342	1 ☐ Yes 2 ☐ No — *SKIP to* 2e
d. Is. . . able to do this at all?	8344	1 ☐ Yes 2 ☐ No
e. Does.. . have any trouble having his/her **speech** understood?	8346	1 ☐ Yes 2 ☐ No
MARK BY OBSERVATION IF APPARENT. **3.** Does... generally use an aid to help . . . get around such as crutches, a cane, or a wheelchair?	8348	1 ☐ *Yes* 2 ☐ No
4a. These next questions ask **whether . . .'s** health or condition affects. . .'s ability to do certain activities. *(If person uses special aids, ask about the* ability *to* do the activity while using *the* special *aids.)* Does . . . have any **difficulty** lifting and carrying something as heavy as 10 lbs., such as a full bag of **groceries?**	8350	1 ☐ Yes 2 ☐ No — *SKIP to 4c*
b. Is. . . able to do this at all?	8352	1 ☐ Yes 2 ☐ No
c. Does . . . have any difficulty walking for a quarter of a mile — about 3 city blocks?	8354	1 ☐ Yes 2 ☐ No — *SKIP to 4e*
d. IS . . . able to do this at all?	8356	1 ☐ Yes 2 ☐ No
e. Does . . . have any difficulty walking up a flight of stairs without resting?	8358	1 ☐ IYes 2 ☐ No — *SKIP to 4g*
f. Is . . . able to walk up **a** flight of **stairs** without the help of another **person?**	8360	1 ☐ Yes 2 ☐ No
g. Does . . . have any difficulty getting ● rwnd outside the house by.. .'s self?	8362	1 ☐ Yes 2 ☐ No — *SKIP to 6a*
h. Does.. . need the help of another person in order to get around **outside** the house?	8364	1 ☐ Yes 2 ☐ No
i. Does. . . **have** any difficulty gattlng ● rwnd inside the house by. . .'s self?	8366	1 ☐ Yes 2 ☐ No — *SKIP to 4k*
j. . need the help of another person in **order** to get around inside the **house?**	8368	1 Y e s 2 ☐ No
k. Does . . . **of.'sad by . .**	8370	1 ☐ Yes 2 ☐ No — SKIP to *Check Item T18*
l. Does... **toget**	8372	1 ☐ Yes 2 ☐ No
CHECK ITEM T18 *Refer to items 4h. 4j and 4l above.* Does . . need the help of another person in order to get around or get in and out of bed?	8374	1 ☐ Yes 2 ☐ No — *SKIP to 6a*

Section 5 — TOPICAL MODULES — Continued

Part B — HEALTH AND DISABILITY — Continued

5a. You **mentioned** that. . . **needed help (getting** around/getting in and out of **bed.)**

Who usually helps . . . **(get around/get** in and **out** of **bed)?**

Mark *(X) all that apply.*

SOMEONE FROM OUTSIDE THE HOUSEHOLD
- 8376 1 ☐ Relative
- 8378 2 ☐ Friend/neighbor
- 8380 3 ☐ Paid employee
- 8382 4 ☐ Someone from a nonprofit organization or agency

HOUSEHOLD MEMBER
- 8384 5 ☐ Relative
- 8386 6 ☐ Paid employee
- 8388 7 ☐ Other nonrelative
- 8390 8 ☐ Does not receive help — *SKIP to 5c*

ASK OR VERIFY —

b. Does . . . (or . . .'s family) pay for **any** of **the** help that.. **.receives?**

8392 1 ☐ Yes
2 ☐ No

(SHOW FLASHCARD *W)*

C. What health **condition** is **the** main **reason...** has **trouble getting** around?

8394 Code ☐☐ Name of health condition

6a. Because of.. **.'s** health, **does . . . need help** to *do* light **housework** such as washing **dishes,** straightening up, or light cleaning?

8396 1 ☐ Yes
2 ☐ No

b. Does... **need help** to **prepare meals** for. **..'s self?**

8398 1 ☐ Yes
2 ☐ No

CHECK ITEM T19 Does. . . need help to do housework or prepare meals (is "Yes" marked in either 6a or 6b)?

8400 1 ☐ Yes
2 ☐ No — *SKIP to 8a*

7a. Who generally **helps . . . with (housework/meal preparation)?**

Mark *(X) all* that *apply.*

SOMEONE FROM OUTSIDE **THE** HOUSEHOLD
- 8402 1 ☐ Relative
- 8404 2 ☐ Friend/neighbor
- 8406 3 ☐ Paid employee
- 8408 4 ☐ Someone from a nonprofit organization or agency

HOUSEHOLD **MEMBER**
- 8410 5 ☐ Relative
- 8412 6 ☐ Paid employee
- 8414 7 ☐ Other nonrelative
- 8416 8 ☐ Does not receive help — *SKIP to 7c*

ASK OR *VERIFY* —

b. Door. . . (or. **..'s family) pay** for **any** of **the help that . . . receives** with **(housework/meal preparation)?**

8418 1 ☐ Yes
2 ☐ No

C. During the past 4 months has . . . **received any meals** provided by • **community service** • ithr **delivered** to **home** or **served** in • group **setting?**

8420 1 ☐ Yes
2 ☐ No

ASK OR VERIFY —

(SHOW FLASHCARD W)

d. What **health condition** is **the** main **reason** . . . is **unable** to (do **housework/prepare meals)?**

8422 N,Code m e o f h e a l t h condition

8a. Does . . . need help from **others** In **looking after personal needs** such **as dressing, undressing, eating,** or **personal hygiene?**

8424 1 ☐ Yes
2 ☐ No — *SKIP to Check item T20*

b. Who **generally helps . . . with** such things?

Mark *(X) all* that apply.

SOMEONE FROM OUTSIDE **THE** HOUSEHOLD
- 8426 1 ☐ Relative
- 8428 2 ☐ Friend/neighbor
- 8430 3 ☐ Paid employee
- 8432 4 ☐ Someone from a nonprofit organization or agencv

HOUSEHOLD **MEMBER**
- 8434 5 ☐ Relative
- 8436 6 ☐ Paid employee
- 8438 7 ☐ Other nonrelative
- 8440 8 ☐ Does not receive help — *SKIP to Check Item T20*

ASK OR VERIFY —

C. Does . . . (or . . .'s family) pay for **any** of **the help** that. . . **receives** in looking **after his/her personal needs?**

8442 1 ☐ Yes
2 ☐ No

CHECK ITEM T20 Refer to Control Card *item* 24.

What is. . .'s age?

8444
1 ☐ 15 years — *SKIP to 13a*
2 ☐ 16 to 72 years
3 ☐ 73 years or over — *SKIP to 13a*

Section 5 — TOPICAL MODULES — Continued

Part B — HEALTH AND DISABILITY — Continued

CHECK ITEM T21 Is "Disabled" marked on the ISS for . . .? [8446] 1 ☐ Yes — SKIP to 9a 2 ☐ No

CHECK ITEM T22 Is "Disabled" marked on the control card for. .? [8448] 1 ☐ Yes 2 ☐ No — SKIP to 9b

9a. We have recorded that . . .'s health or condition limits the kind or amount of work . . . can do. Is that correct? [8450] 1 ☐ Yes — SKIP to 9c 2 ☐ No — SKIP to 13a

b. Does.. .'s health or condition limit the kind or amount of work.. . can do? [8452] 1 ☐ Yes — Mark "171" on ISS 2 ☐ No — SKIP to 13a

c. In what year did. . . bacoma limited in the kind or amount of work that. .. could do at a job? [8454] 1 9 ☐ ☐ — If 1984 ask 9d, otherwise SKIP to 9e

OR

1 ☐ Person was limited before person became of working age — SKIP to 10a

d. In what month did . . . become limited? Enter numeric code. [8456] ☐☐ Month

e. Was.. . employed at tha time . . .'s work limitation began? [8458] 1 ☐ Yes — SKIP to 10a 2 ☐ No

f. When was the last time. .. worked bafora . . .'s work limitation began? [8460] 1 9 ☐ ☐

OR

1 ☐ Had never been employed before work limitation began

ASK OR VERIFY — (SHOW FLASHCARD WI

10a. What health conditon is tha main reason for . . .'s work limitation? [8462] Code ☐☐ Name of health condition

ASK OR VERIFY —

b. Was this condition caused by an accident or injury7 [8464] 1 ☐ Yes 2 ☐ No — SKIP to Check Item T23

c. Where did the accident or injury take place — was it (Read categories) — Mark (X) only one. [8466] 1 ☐ On Your job7 2 ☐ During service in tha Armed Forces? 3 ☐ In your home? 4 ☐ Somawhan else?

CHECK ITEM T23 Is "Worked" marked on the ISS? [8468] 1 ☐ Yes — SKIP to Check Item T24 2 ☐ No

11a. Does . . .'s health or condition prevent . . . from working at a job or business? [8470] 1 ☐ Yes 2 ☐ No — SKIP to 12a

b. In what year did . . . become unable to work at a job? [8472] 1 9 ☐ ☐ — If 1984 ask 11c, otherwise SKIP to 13a

OR

1 ☐ Has never been able to work at a job SKIP to 13a

c. In what month did . . . become unable to work7 Enter numeric code. [8474] ☐☐ Month } SKIP to 13a

CHECK ITEM T24 Refer to item 8a, page 4. Did. . . usually work 35 or more hours per week during the reference period7 [8476] 1 ☐ Yes — SKIP to 12b 2 ☐ No

12a. Is.. . now able to work at a full-time job or is . . . only ● bla to work part-time? [8478] 1 ☐ Full time 2 ☐ Part time

b. Is . . . now able to work regularly or is . . . only ● ble to work occasionally or irregularly? [8480] 1 ☐ Regularly 2 ☐ Only occasionally or irregularly

Section 5 — TOPICAL MODULES — Continued

Part B — HEALTH AND DISABILITY — Continued

2c. Ia... now able to do tha aama klnd of work ... did before ...'s work limitation began?

8482
1 ☐ Yes, able to do same kind of work
2 ☐ No, not able to do same kind of work
3 ☐ Did not work before limitation began

3a. During the past 12 months, was... patlant in a hospital overnight or longer?

8484
1 ☐ Yes
2 ☐ No — *SKIP to* 14

b. How many different times did... stay in a hospital overnight or longer during the past 12 months?

8486 ☐☐ Times

c. Was... a patient in a VA or military hospital during (this visit/any of these visits)?

8488
1 ☐ Yes
2 ☐ No

d. How many nlghta in all did... spend in a hospital during the past 12 months?

☐☐☐ Nights

e. How many of these nights were in the past 4 months?

8492
x5 ☐ All nights
OR
8494 ☐☐☐ Nights
OR
x3 ☐ None

14. During the past 4 months, about how many days did illness or injury keep... in bed more than half of the day? (Include days while an overnight patient in a hospital.)

8496
x5 ☐ All days
OR
☐☐☐ Days
OR
x3 ☐ None

15a. During the past 12 months, how many times dld ... an or talk to a medical doctor or aaiatant? (Do not count octuwancaa while an overnight patient in a hospital.)

8498 ☐☐ (Times
OR
x3 ☐ None — *SK/P to 16a*

b. HOW many of thaaa visits or calls were in the past 4 months?

8500 ☐☐ Times
OR
x3 ☐ None

16a. Ia there a particular clinic, health cantor, doctor's office or some other place where ... usually goes if ... is sick or needs advice about...'a health?

8502
1 ☐ YSS
2 ☐ No — SK/P to *Check kern T25*

b. TO what kind of place does... usually go?
Mark *(X) only* one.

8504
1 ☐ Doctor's office (private doctor)
2 ☐ VA or military hospital
3 ☐ Hospital outpatient clinic (not VA or military)
4 ☐ Hospital emergency room
5 ☐ Company or industry clinic
6 ☐ Health center (neighborhood health center or free or low-cost clinic)
7 ☐ Other — Specify _____

CHECK ITEM T25

Refer to item 27a, page 10.
Is covered by a private health insurance; plan in...'s own name?

8506
1 ☐ Yes
2 ☐ No — *SKIP to Check Item T27*

17a. We laamad arlior that... hod health insurance. What is the name of...'a health insurance plan?

8508
1 ☐ Blue Cross/Blue Shield
2 ☐ Other — *Specify* _____
x1 ☐ DK

b. Does...'s health Inauranca pay for the complete coat of a doctor visit?
Mark "No" *if policy requires a deductible.*

8510
1 ☐ Yes
2 ☐ No
x1 ☐ DK

FORM SIPP 4300 (12 12 80)

APPENDIX B

SPECIFICATIONS FOR CLASSIFICATION OF LIMITATIONS IN FUNCTIONING

APPENDIX B

A SIX-LEVEL CATEGORIZATION OF DISABILITY
BASED ON LIMITATIONS IN FUNCTIONING
AND RESPONSES TO SIPP

Level and Degree of Limitation		Definition
I.	Needs assistance with Activities of Daily Living (ADLs)	The sample member needs the help of another person with personal needs (dressing, undressing, eating, or personal hygiene), in getting in and out of bed, or in ambulating inside the house.
II.	Needs assistance with Instrumental Activities of Daily Living (IADLs), but not with ADLs	The sample member needs the help of another person in doing light housework, in preparing meals, or in ambulating outside the house, but does not need assistance with ADLs.
III.	Inability to perform one or more functions, or has difficulty with two ADLs, yet reports no need for assistance	The sample metier either (1) reports an inability to perform one or more of the functions of seeina. hearina.. liftina 10 lbs.. walking 3 cit blocks, or climbing a-flight of stairs: or (23 reports difficulty in adulating inside the house and in getting in and out of bed. The sample member does not report needing assistance with ADLs or IADLs.
IV.	Has difficulty in two or more functions, but does not report any inabilities in functions or the need for assistance	The sample metier reports difficulty in performing two or more of the following functions: seeing, hearing, speaking, lifting 10 lbs., walking 3 city blocks, climbing a flight of stairs, or ambulating outside the house. The sample member does not report an inabiiity to perform any one of these functions or a need for assistance with ADLs or IADLs.
V.	Has difficulty only in one function, no inabilities in functions, and no need for assistance	The sample member reports difficulty only in one of the above functions.
VI.	Has no limitation in functioning	Sample member does not report any type of limitation, inability, or need for assistance.

NOTE: For presentational purposes, Levels I and II are combined to identify persons needing assistance with ADLs or IADLs; Levels III and IV are combined to identify persons with substantial physical or sensory limitations: persons in Level V are considered as having mild physical or sensory limitations.

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THE ACTIVITIES OF DAILY LIVING, NATIONAL SURVEYS AND LONG TERM CARE COST ESTIMATES: TWO CURRENT INITIATIVES

by

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BACKGROUND

As developed by Sidney Katz and his colleagues (1963), the Activities of Daily Living (ADL) -- eating, continence, transferring in and out of bed, toileting, dressing and bathing -- have made it possible to analyze "detailed observations of many basic activities of patients with chronic conditions" (Katz, S. and Akpom, C.A., 1976, p. 117). The Guttman-scaling (or hierarchic-, al) properties of the Katz ADL scale have made it easier to track the rehabilitative progress of impaired persons.

In part because of their success in clinical settings, ADLs have also come to play a major role in large national surveys covering the long term care population. They serve as a "handle" with which researchers count the number of elderly persons who are functionally disabled, identify the types and severity of those disabilities and assess the adequacy of long term care settings and services (e.g. Liu, K., Manton, K.G., and Liu, B.M., 1982; Manton, K.M.,1988; Stone, R.I. and Murtaugh, C.M., 1989).

With increasing frequency, ADL limitations have been written into a number of congressional bills as criteria for determining the eligibility of Medicare beneficiaries for proposed long term care benefits. Before his death, Representative Claude Pepper initiated this trend.

Under H.R. 3436 (the Pepper Bill), introduced into the 100th Congress, a chronically ill individual eligible for service meant in part one certified as "being unable to perform (without substantial assistance from another individual) at least two activities of daily living..."

For the first session of the 101st Congress, the chief sponsors of long term care bills that incorporate ADLS include Senators Kennedy, Bradley, and Rockefeller as well as Representatives Wyden and Waxman. The costs of the proposed benefits depend in part on the number of persons made eligible for them by the ADL eligibility criteria.

EASY QUESTIONS. NOT SO EASY ANSWERS

For survey research and policy analysis, it thus seems reasonable to employ ADLs in addressing the following questions.

(1) What is the number of functionally disabled elderly persons nationally?

(2) What is the number of elderly persons made eligible under various long term care benefit proposals?

The answers to these questions are by no means as straightforward as one might think. Estimating the extent of functional disabilities with ADLs is possible, but not easy. (Of course, estimating without an ADL-like framework might not be feasible at all.) There are in fact considerable differences in the published estimates of functionally disabled elderly based on national survey data where information on ADLs is collected.

For example, one study using the 1984 Survey of Income and Program Participation (SIPP) found 1.5 million persons with "personal care needs"; another using the 1982 National Long Term Care Survey identified 3.0 million persons disabled in one or more ADLs; and a third, using the 1984 Health Interview Survey/Supplement on Aging found 6.0 million impaired elderly (Wiener, 1989, P.2).

These in turn have contributed to wide discrepancies in estimating the costs of various long term care benefit proposals.

If we imagine that all these persons were eligible for a public long term care benefit, whose average annual per capita cost was $1000, the cost estimates nationally would range from $1.5 billion to $6.0 billion a year, depending on which study undergirded the estimate.

The rest of this paper focuses on several problems associated with making estimates using ADLs and highlights some of the methodological work carried out or sponsored by the Department of Health and Human Services to overcome these problems.

For survey research, the problems associated with ADLs can be summarized as follows.

(1) <u>There is no standard set of ADLs across national surveys.</u>

Most surveys include a set of five "core" ADLs -- eating (or feeding), getting in and out of bed, toileting, dressing and bathing. Other ADLs found in many surveys include: (a) urinary and bowel continence -- sometimes separated, sometimes combined; (b) getting in and out of chairs: (c) getting around inside; and (d) walking.

In the 1982 and 1984 National Long Term Care Surveys (NLTCS), for example, nine ADLs are used in the screener, while six are covered in the detailed interview. The 1984 National Health Interview Survey/Supplement on Aging (HIS/SOA) also uses nine ADLs in its screening questions (though not exactly the same nine as in the NLTCS) and seven in the more detailed questions. The 1987 National Medical

Expenditure Survey/Household Component uses seven screener ADLs and six for detailed questions.

(2) The questions aimed at identifvins ADL limitations vary within and across surveys.

How survey respondents are determined to be or not be ADL-impaired depends on (a) the kinds of questions asked and (b) the selection among those questions made by analysts for making their determinations. For screening purposes, the NLTCS made a respondent eligible for the detailed interview if he or she indicated an ADL problem that lasted or was expected to last at least three months. In contrast, the 1984 HIS/SOA screening questions ask about current difficulty with ADLs.

The detailed questions include factors like: (a) ability to perform ADLs versus actual performance; (b) degree of difficulty in performing ADLs; (c) whether or not human assistance was provided and whether the assistance was active or standby; and (d) use of mechanical aids in performing ADLs. Not all these types of questions are included on every survey. Even when the same types of questions are included on two separate surveys, the different ways that questions are worded can affect response rates.

Even when the data are available, analysts may use different criteria to determine the presence of functional disability. Some, for example, use human assistance alone as a measure while others incorporate use of mechanical aids as well. Even within human assistance, some draw- a distinction between active and standby (or supervisory) assistance.

(3) Survey design factors can affect the estimates of ADL-impaired elderly.

These factors can include: (a) the year in which the survey was administered; (b) the sampling frame used to generate the survey sample: and (c) data collection procedures. Since persons age 85 and over, who are more likely to be disabled, are an increasingly higher percentage of the total elderly population, more recent surveys can be expected to show higher rates of disability.

The sampling frame for national surveys can account for some variation among response rates. The NLTCS sample frame was a file of Medicare enrolles, the HIS relies on a sample of the civilian non-institutionalized population and the NMES was a year-long panel of a Census sample of 14,000 households.

Differences in data collection procedures include: (a) face-to--face versus telephone interviews; (b) rate of proxy respondents: (c) skip patterns in the progression of questions; and (d) time intervals (e.g. administering a screener at a different time from the detailed interview questions).

All these factors have some probable -- though as yet unmeasured -- effect on differences in the rates of functional disability generated by these surveys.

I now want to turn to two initiatives, one completed and one in progress, designed to make more effective use of ADLs in analyses of the functionally disabled elderly population.

THE FORUM ON AGING-RELATED STATISTICS

The first initiative addresses the first question raised above -- namely, the number of functionally disabled persons nationally. The second addresses the second question -- the number of persons eligible for various long term care benefits where ADLs serve as eligibility criteria.

In May, 1988, the federal Interagency Forum on Aging Related Statistics established a committee to compare the results of national surveys that use ADLs to measure functional disability. The Forum, whose co-chairs are the Directors, respectively, of the Census Bureau, the National Institute on Aging and the National Center for Health Statistics, sought to account for differences across these surveys, which in turn have affected cost estimates of proposed long term care legislation.

The Committee on Estimates of ADLs in National Surveys identified eleven national surveys that used ADLs. Among the factors that account for differences across surveys and that, for comparative purposes, could be standardized was the number of ADLs in the surveys and the wording of questions about them.

Thus, all the surveys included the five core ADLs, namely, eating, toileting, transferring in and out of bed, dressing and bathing. The question applied commonly across all surveys was whether or not the respondent received the help of another person with one or more of the core ADLs.

Table 1, which is reproduced from the report of the committee to the Forum, shows how the results vary for five of the national surveys that focused on the noninstitutionalized elderly population.

As you can see, the number of persons (and percent of the total elderly population) receiving the help of another person with one or more ADLS was:

2,250,000 (8.1%) from the 1987 NMES
2,062,000 (7.8%) from the 1984 NLTCS
1,992,000 (7.8%) from the 1982 NLTCS
1,538,000 (5.8%) from the 1984 SIPP and
1,318,000 (5.0%) from the 1984 HIS/SOA

The numbers range from 2.25 million or 8.1% of the elderly population down to 1.32 million or 5.0% of the elderly population. How significant these differences are may lie in the eye of the beholder. The difference between the highest and lowest estimates of the percent of the population with ADL impairments is 3.1%. However, looked at from another angle, we see that the highest number is 60% greater than the lowest.

These are the results when one attempts to standardize the number of ADLs covered and the types of questions asked. The differences can be expected to be larger when analysts use different sets of ADLs and different questions.

It seems reasonable to ask that, in reporting their results, analysts provide information on how they defined ADL disability and which data elements were used. Survey designers need to be cognizant of different research foci. From a policy perspective, receipt of assistance and unmet needs are key issues. From an epidemiological perspective, information is needed on the underlying causes of ADL disabilities and the exact nature of the dysfunction.

To facilitate comparisons with other research findings, analysts should provide a standard set of tabulations using the approach of the Forum's ADL committee -- namely, the number of persons receiving help with the five core ADLs.

REAL WORLD APPLICATIONS

The second initiative concerns ongoing work being sponsored by the DHHS' Office of the Assistant Secretary for Planning and Evaluation through a contract with SysteMetrics, Inc.

SysteMetrics, Inc. is in the process of carrying out three major tasks under this contract:

(1) Reviewina the eliaibility provisions of existina and proposed long term care benefit proposals.

This entails identifying policy options and congressional bills where functional disability as indicated by ADL limitations is used to determine eligibility for benefits. The contractor is also looking at how eligibility is determined under existing long term care vehicles like Medi-

care, Medicaid, state-funded community care programs and private long term care insurance.

(2) Examining existing national data sets for their utility in estimating eligibility for and costs of expanded long term care benefits.

The study carried out for the Interagency Forum on Aging Related Statistics provides an excellent starting point for this activity. However that study was primarily methodological. The numbers it generated were used for purposes of comparison across surveys, not for yielding actual prevalence estimates. SysteMetrics will endeavor to produce defensible prevalence estimates both of the entire long term care population and for groups eligible for various proposed long term care benefits.

This work involves developing alternative operational definitions of functional disability that address such factors as: (a) the inclusion of Instrumental Activities of Daily Living (IADL) and cognitive impairments as well as ADLs; (b) the role of mechanical aids along with human assistance in carrying out daily activities: (c) whether to emphasize capacity to perform or actual performance of activities: (d) the extent to which unmet or undermet needs can be covered; and (e) the ability of surveys to discriminate within functional disabilities by level of severity.

(3) Developing estimates of persons eligible for long term care benefits under current legislative proposals.

The contractor will make population estimates of the number of persons covered under various long term care bills, using alternative definitions of functional disability. Additionally, the contractor will generate cost estimates for these bills, based on assumptions concerning: (a) participation rates: (b) unit costs of covered services; (c) frequency of service use: and (d) intensity of service use.

Already this contract has yielded a report on the extent to which functional criteria are used in existing programs and current legislative proposals, plus the policy implications of using ADLs to allocate long term care benefits (Jackson, M.E. and Burwell, B.O., 1989).

CONCLUSION

The two initiatives outlined in this paper -- the study of ADLs across national surveys sponsored by the Forum on Aging Related Statistics and the estimates of covered populations and costs

under various long term care bills being prepared by **SysteMetrics** -- will strengthen our ability to assess the strengths and weaknesses of alternative long term care initiatives. They will also provide guidance on how best to use national survey data and **ADLs** in making these estimates.

While our understanding of how to measure functional disability using **ADLs** has improved, additional work is needed. For example, it is not clear that ADL limitations in non-institutional settings mean the same thing as ADL limitations in institutional settings. The applicability of **ADLs** to the non-elderly requiring long term care needs study. The kind of methodological work done on **ADLs** needs to be carried forward to **IADLs,** and, more critically, to cognitive impairments, which are often proposed along with **ADLs** as eligibility criteria for long term care benefits.

Finally, we need to examine more closely the relationship between measures of disability and the allocation of resources. Persons with the same ADL disabilities have very different needs depending on the availability of informal caregivers, technological aids, and environmental modifications in housing and in the community. The challenge in policy development is how to use disability criteria in association with other factors to distribute resources, control costs and meet long term care needs.

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