

# Statistical Analyses Based on the National Health Interview Survey on Disability: A Bibliography and Summary of Findings<sup>1</sup>

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## I. An overview of the NHIS-D

In an effort to meet the historical and political need for information on disability, four Federal offices (the Office of the Assistant Secretary for Planning and Evaluation, Health and Human Services (OASPE); Office of Planning and Security Income, Social Security Administration (SSA); Office of Disability, SSA; and Bureau of Maternal and Child Health, Health Resources and Services Administration) planned several national surveys about various aspects of disability in the early 1990's.

Because many of these Federal offices had overlapping disability interests, their efforts were merged into one survey that was conducted as part of the National Health Interview Survey (NHIS) for two consecutive years, 1994 and 1995. The NHIS is an annual survey of the civilian noninstitutionalized population of the United States conducted by the National Center for Health Statistics (NCHS). After the initial planning stage of the disability survey, other organizations with an interest in disability participated. NCHS, OASPE, and the other consortium members jointly planned the survey, and the Bureau of the Census conducted the field work. The survey became known as the National Health Interview Survey of Disability, or NHIS-D.

The NHIS-D, a supplement to the annual NHIS, was done in two phases. NHIS-D, Phase I, questions were administered concurrently with the NHIS basic questionnaire or "core" in 1994 and 1995. Disability information for all household members was obtained from the adult family members present at the time of interview. The Phase I questionnaire included basic questions about disability and was used as a screening device to determine eligibility for NHIS-D, Phase II. Because disabilities occur infrequently within the noninstitutionalized civilian population, NHIS-D, Phase I, was fielded over a 2-year period. The two-phase design allowed the collection of more data without causing the potentially damaging effects of using one very long questionnaire.

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Phase II of the NHIS-D was a follow-up survey of people identified in Phase I as having a disability, defined as an impairment, limitation in activity, use of assistive devices or services, participation in disability programs, or being perceived to have a disability. Phase II was fielded beginning in 1994 and completed in the spring of 1997. Most Phase II interviews were done face-to-face with sample adults or a parent of sample children. Altogether, disability information was obtained on more than 200,000 persons in Phase I and about 33,000 persons in Phase II.

Because of the large size and scientific design of its sample, the comprehensive coverage of its questionnaires, and the high standards of its field operations, the NHIS-D was a unique source for statistical information about disability in the United States near the end of the 20<sup>th</sup> Century.

## II. Methods for identifying publications

The goal of the project was to identify all publications that were based on original analyses of data from the 1994-1995 National Health Interview Survey on Disability. The search began with PubMed, the search engine of the National Library of Medicine at the National Institutes of Health. PubMed contains bibliographic citations and author abstracts from more than 4,800 biomedical journals published in the United States and 70 other countries. Searches were conducted using combinations of several key words: “National Health Interview Survey,” “NHIS,” “National Health Interview Survey on Disability,” “NHIS-D,” “national survey,” “disability,” “impairment,” and “activity limitation.” Searches were limited to the English language and publication dates in 1990 or later.

Citations returned by PubMed were read and eliminated if they indicated that the publication was not based on the NHIS-D (e.g., a publication whose title indicated the “national survey on disability” identified had been conducted outside the U.S.). The abstracts for the remaining citations were read, and irrelevant citations were similarly eliminated on the basis of information in the abstracts. The citations and abstracts of publications that were definitely, or probably, based on the NHIS-D were saved to a file.

If the full text of the selected publications was available online at no cost or at a reasonable cost, it was downloaded. If the full text could not be obtained online, photocopies were made from the collections of the University of Minnesota library system. As another step in the search for publications, the full text publications were scanned for citations of previous publications based on the NHIS-D. When new citations were identified they were added to the citations file, and when possible, the full text of the publications was obtained.

When this search procedure reached a point where few new publications were being identified, an author of each publication was E-mailed a list of the citations for their publications, asked to review them for accuracy, and asked to add relevant citations not included on the list. The authors contacted were an author of each of the publication citations they were sent, and lead author on at least one of those publications. Authors were very cooperative in responding to these requests, and many supplied additional citations for publications that were recent, forthcoming, or in journals not indexed by PubMed.

### III. Categories of publications identified

During the search process, three files were maintained: abstracts, full text articles, and a summary spread sheet. The summary spread sheet included the complete bibliographic citation and links to the corresponding entries in the files of abstracts and full text articles. The next step was to organize the publications into groups for presentation and review. That process comprised the following steps.

Based on the available information about each publication, they were assigned one or two key words identifying the central topic of the publication or the population on which it focused. Thus, for example, a publication that described development of a new method for defining disability among children would have been assigned the key words “methods” and “children.” The publications were sorted by key words to create an initial set of groups. By examining the content of the initial groups, labels for larger groups were created; in the process, decisions were made about where to classify publications that could have been placed in more than one group, such as “children” or “methods.”

The decisions were sometimes arbitrary, but often they were made to create groups of publications that together “tell a story.” Thus, whereas the interest of the author(s) may have been primarily in the substance of child disability, if the publication’s approach to measuring child disability was an important part of the story about methodological developments, it may have been placed in the “methods” group.

Groupings were also influenced by perceptions of the boundaries of natural “research communities.” There is a community of scholars in the field of child disability, for instance, who tend to publish in the same journals, cite each other’s work, attend the same conferences, etc. Similarly, there is a community of scholars whose primary interest is disability survey methodology. Publications were grouped and labeled to help the members of those communities find the NHIS-D publications of primary interest to them.

The result of this process was a grouping of the NHIS-D publications in five labeled categories and one “out-of-scope” category. The scope of each category is briefly discussed here.

- a. Methods. Some design features of the NHIS-D make it a useful data set for methodological studies, and fifteen of the publications fall into this category. The methodological studies are of two broad types: development and comparison of different measures of disability and issues in questionnaire design and field administration.
- b. AT and PAS services. The NHIS-D was relatively rich in information about assistive technology (AT) and personal assistance services (PAS), and ten publications are in this category. Two publications focus on assistive technology, four on personal assistance services, and four on the relationship between AT and PAS—that is, the extent to which AT “substitutes” for PAS or *vice versa*.

- c. Policy issues: cost, employment, and health care. Publications in other categories may have implications for policy as well, but the 19 publications in this category were largely motivated by issues currently under debate. Because the policy debate is largely about the costs of income benefits and health care for persons with disabilities, there are publications on cost, employment, and health care.
- d. Populations of special interest: children, women, and minorities. There has been an especially large production of NHIS-D publications on children with disabilities—a total of twenty. By contrast, there have been only two publications focusing on women, and only one focusing on racial comparisons. There were sufficient numbers of publications on children to create sub-categories such as insurance coverage and family impact.
- e. Types of disability: mobility, sensory, mental, and MR/DD. While most of the publications in other categories use inclusive definitions of disability, the 27 publications in this section focus on one type of disability: mobility, sensory, mental, and MR/DD. Some focus on a particular policy issue or special population, and could have been put in those categories also.
- f. Out-of-scope. Publications could be “out-of-scope” for two reasons. First, they were not based on original analyses of NHIS-D data, even though they were about the NHIS-D; for example, a commentary on policy implications of the NHIS-D. Second, although they did include original analyses of NHIS-D data, that was not the primary source of the data presented; for example, compilations of data from many sources.

## IV. Summary of findings by category

### a. INTRODUCTION

In this section the key findings of publications based on the NHIS-D will be narrated briefly, organized into broad categories of subject matter. For this purpose, only those publications that make original use of data from the survey will be included--publications that describe the survey or comment on its design and uses are not included; also, publications in which the NHIS-D data are included in a general compilation of data from many sources are not included.

Many of the publications are on topics that fit into more than one of the categories used to organize the narrative. Each will be discussed primarily in one narrative category, but where applicable, they will be cited in the narrative for other categories.

The boldface, indented statements are brief statements of findings from specific publications that summarize a key finding. The key findings are not necessarily those identified by the author(s) of the publications; they may instead highlight a finding that is key in the context of other publications discussed in the same category.

The key findings are followed by brief paragraphs for each that identify the source of the finding and comment on the finding.

## b. METHODS

The NHIS-D used a standard methodology known as the “household interview survey” (Reference). The strengths and weakness of that methodology have been extensively studied, leading to continuous efforts to improve survey design. The NHIS-D provided an unusual opportunity to study household interview survey methods in relation to the particular subject of disability. Furthermore, the design of the NHIS-D had some features that facilitated methodological study, such as large sample size, multiple disability measures, and multiple interviews. A number of researchers have taken advantage of these features of the NHIS-D to study the methodology of disability surveys.

### NEW METHODS FOR OPERATIONALLY DEFINING DISABILITY

**Although the official definitions of intellectual and developmental disabilities are complex, they can be defined operationally using the National Health Interview Survey on Disability, permitting estimates of the size and characteristics of those populations.**

The fact that the NHIS-D designers did not adopt any single definition of disability, but instead collected a wide variety of disability indicators intended to be useful for a variety of applications, enabled researchers to develop *ex post facto* definitions of disability to suit their research needs. The work of Larson, Lakin, Anderson, Kwak, & Anderson (2001), is a good example. These researchers wanted to make accurate national estimates of the number and characteristics of children and adults who met the official criteria for “mental retardation” and “developmental disability” as used by several programs of the U.S. Federal Government. By combining data from many different sections of the questionnaires and several different files, they were able to operationalize the official definition with great precision, making it possible to undertake a series of studies of these populations that had never before been possible. (Those studies are discussed further in the section of Types of Disability.)

**An operational definition of disability derived from the theoretically-based and rigorously tested Questionnaire for Identifying Children with Chronic Conditions (QuICCC) was successfully used to estimate prevalence with the National Health Interview Survey on Disability.**

Another group of researchers led by Ruth Stein, a medical and public health researcher, was interested in studying the population of children who need medical care of a type, frequency, or duration of that goes beyond that needed by most children. These “children with special health care needs” are very important for programs of the Maternal and Child Health Bureau. Stein and colleagues developed a detailed instrument for identifying those children called the Questionnaire for Identifying Children with Chronic Conditions (QuICCC) that was tested for reliability and validity in a number of small scale studies. Some of those researchers were

consulted during the development of the NHIS-D and many questions similar to those in the QuICCC were adopted. Consequently, it was possible for the Stein and Silver (1999) to create a measure from the NHIS-D closely approximating the QuICCC and to make national estimates of statistics for that population, some of which are discussed in the section on Populations of Special Interest.

Paul Newacheck, another public health researcher interested in child disability, led an effort to operationally define a somewhat different measure, based on the consensus definition of “children with special health care needs” developed under the auspices of the Maternal and Child Health Bureau (Newacheck et al., 1998). That measure was very similar to the QuICCC developed by Stein; in fact, some of the same researchers participated in both efforts. The measure developed by Newacheck has been used by him and others in a series of studies of child disability discussed in the section on Populations of Special Interest.

**A new measure of functional limitations in mobility, communication, self care, and learning, shows that 8.1% of school-age children have a serious disability, and another 4.1% have a mild disability.**

Dennis Hogan and colleagues at Brown University, working out of another disciplinary tradition, demography, undertook to develop a different definition of childhood disability (Hogan, Msall, Rogers, & Avery, 1997). Following the theoretical framework of the National Center for Medical and Rehabilitation Research and previous work on another measure of child functioning (the WeeFIM), their definition focuses on four functions: mobility, self care, communication, and learning. Using conventional scale construction methods, measures of each function were created from NHIS-D questions about children and their families. A useful feature of the scales is that they are numerically scored to indicate the severity of limitation for each function, and the scores can be summed across functions to create a summary disability severity measure for each child. In subsequent work, Hogan, his colleagues, and other researchers have used these measures to analyze several aspects of childhood disability.

**Different definitions of childhood disability applied to the same data set yielded estimates of prevalence from 13.7-17.0%, and there is substantial overlap in the individual children included by different definitions.**

The existence of multiple operational definitions of disability invites comparison among them. Often such comparisons are confounded by differences in the data sets used for the different definitions. The richness of data available in the NHIS-D has made it possible to compare different definitions of disability using the same data set, thereby holding constant one possible cause of differences between the results. Stein and Silver (2002) undertook such a comparison among different operational definitions of child disability: Stein’s measure, the measure developed by Newacheck and others, a measure developed by New England SERVE, and the algorithm used to select the NHIS-D Phase 1 children who were eligible for Phase 2. The last of these was not intended as an operational definition of disability, but was so regarded in this study. Stein and Silver conclude that the four definitions are very comparable, and that findings based on any one definition are robust across the other definitions.

**Comparison of estimates of the prevalence of disability using three different definitions yields estimates ranging from 9% to 14% of children. Choice of a definition affects estimates of the proportion of children with disabilities who use ancillary services such as therapy (26-30%) and enabling services such as special equipment (11-14%).**

Benedict and Farel (2003) studied variations in the definitions of childhood disability developed by Newacheck, Stein, and Hogan, analyzing their logical structure, comparing the estimates of prevalence they produce, and analyzing their effects on estimates use of ancillary services. Their study is similar to that of Stein and Silver (2002) and reaches similar results.

**Data collected in the National Health Interview Survey on Disability were coded using the WHO International Classification of Functioning, Disability, and Health (ICF) permitting estimates of the prevalence of disabilities in categories that are internationally comparable.**

In 2001 the World Health Organization issued the International Classification of Functioning, Disability, and Health as a standard for classifying and reporting disability statistics. The National Center for Health Statistics, which is the WHO Collaborating Center for the Family of International Classifications in North America, has publicized the ICF and promoted its use. A standard classification can help to improve international communications about disability among health professionals. Many efforts are underway to code existing survey data on disability to the ICF, and one such effort was undertaken by Fedeyko and Lollar (2003) using the NHIS-D. They sorted about 40 NHIS-D questions into the 8 major domains of activity limitation and participation restriction identified by the ICF, then used the NHIS-D data to estimate the prevalence of disability in each of those domains. The study demonstrates that the ICF can be used successfully to code disability data from a survey not designed for that purpose.

#### ISSUES IN QUESTIONNAIRE DESIGN AND ADMINISTRATION

**If people are first asked if they have specific health conditions and then later asked to name the condition causing a disability, they tend to name one of the specific conditions they were asked about earlier, possibly biasing results.**

Two recurring issues in research on survey methodology are questionnaire design and questionnaire administration. Questionnaire design includes the order in which questions in a survey are asked, and questionnaire administration includes rules about who should answer questions: both have been studied using the NHIS-D. With respect to question order, Todorov (2000) showed that people that have been asked in the basic annual NHIS module if they had certain kinds of medical conditions were more likely to name those conditions when they were later asked to name the cause of a disability. For those interested in the medical conditions causing disability, this tendency should be of some concern. It indicates that in surveys making frequent and early mention of specific medical conditions, those conditions can be expected to be more frequently named as causes of disability. This tendency is not necessarily an error, but it does need to be considered in interpreting results.

**People with more severe disabilities are more likely to be interviewed in population-based, face-to-face surveys because they are more likely to be at home and more likely to cooperate; however, interviewers are more likely to substitute proxy respondents for severely disabled sample persons.**

The accuracy of statistics from interview sample surveys of households depends on finding a representative sample of people at home and getting their cooperation for interviews. Hendershot, Colpe, and Hunt (2003) show that people with disabilities are actually very good survey respondents in these respects: more often than other people, they are at home when survey interviewers arrive at their doorstep, and they are more likely than others to cooperate by agreeing to be interviewed. While this is reassuring about the inclusion of people with disabilities in surveys such as the NHIS-D, there is another less favorable finding: a large proportion of sample people with disabilities do not give their own responses; instead, their answers are given by “proxy respondents,” other adults who live in their households. This does not necessarily result in less accurate data, but it may. The issue of reporting by “self” and “proxy” respondents has attracted considerable interest from analysts of the NHIS-D.

**In surveys, whether a person is reported to have a disability depends on the reporter--the person themselves or another family member; this can bias estimates of the prevalence of disability.**

A relatively high rate of proxy respondents for sample persons with disabilities may bias estimates of disability *if* proxy respondents give different answers to questions about disability. Do they? To answer that question, Todorov and Kirchner (2000) examined responses by self and proxy respondents in the NHIS-D. First they compared estimates of disability in Phase 1 by type of respondent, and found that disability was underreported by proxy respondents for sample adults under 65 years of age but overreported for sample persons over that age. They also compared reports of disability from proxy respondents in Phase 1 with reports of disability for the same persons responding for themselves in Phase 2, and found the same pattern. Finally, they rated individual disabilities on observability and found that proxy and self respondents tended to agree if the disability in question was likely to be noticed and to affect social interaction. Clearly, survey estimates of disability may be biased if proxies often respond for sample people with disabilities.

**Proxy respondents are more likely than self respondents to report that sample persons have relatively poor health, but less likely to report that they have a disability.**

Stineman, Ross, Maislin, & Iezzoni (2004) were interested in the effect of differences between proxy- and self-reporting on estimates of health-related quality of life. Among their measures of health-related quality of life were general health status (excellent, very good, good, fair, or poor) and perceptions of disability (whether the respondent or “other people” think the sample person has a disability). After statistical controls for possible confounding factors, they found that proxy respondents were more likely than self respondents to report that a person had poor health, but less likely to report that they were perceived to have a disability.



**Disability is sometimes measured by counting the number of limitations in personal care and home management activities to form a single score, assuming that the two categories measure the same thing and that each increment in the score has the same disability meaning, but those assumptions are not correct.**

Questions about limitations in personal care activities (“Activities of Daily Living”) and home management activities (“Instrumental Activities of Daily Living”) are used to measure disability. As a summary measure, a count of limitations in each type of activity may be used, and for a more general summary, counts of the two types may be summed. Counting or summing limitations identified by different questions assumes that the questions measure the same underlying trait and represent points that are equidistant on a scale (so that, for instance, the difference between scores of 6 and 7 has the same meaning as the difference between 7 and 8). Zhu and Kennedy (2004) investigated those assumptions using data from the NHIS-D, Phase 2 Adult Questionnaire and a technique known as “Rasch analysis” after its developer. Their analysis questions both assumptions: ADL and IADL categories overlap and may represent three scales, not two; and the points on those scales are not necessarily equidistant.

**Measures of disability based on questions about help with activities of personal care or home management assume that different groups interpret questions similarly, but different ages and genders interpret questions differently.**

Measures of disability based on questions about personal care activity (“Activities of Daily Living”) or home management activities (“Instrumental Activities of Daily Living”) assume there is latent trait underlying the measures, and that answers from different groups of people reflect that trait. However, groups may interpret questionnaire items in systematically different ways, so their answers to those items do not refer to the same trait. Such “differential item functioning” can bias comparisons of disability between groups. Flieshman, Spector, and Altman (2002) used a statistical technique to estimate differential item functioning in ADL and IADL questions in the NHIS-D, Phase 1. They found differences in interpretations of some items, especially “shopping” and “money management,” between men and women and between middle aged and older men. Before correcting for this difference, women and middle aged men had lower rates of disability, but after correction the rates were not significantly different.

**Compared to people with few disabilities, people with many disabilities have more severe disabilities and are more likely to have acquired them all at one time.**

A persistent tension in attempts to conceptualize disability is between unity and diversity: is disability a unitary concept with plural dimensions, or is it a diverse set of concepts gathered loosely under a single convenient rubric? In a series of papers, Verbrugge and colleagues (Verbrugge & Yang, 2002; Verbrugge & Yang, 2003; Verbrugge, Yang & Juarez, 2004) contribute to that conceptual discussion by investigating demographic patterns in the timing, number, and severity of disabilities, using data from the NHIS-D, Phase 1. Although many different patterns are logically possible, they find that two patterns account for most disability:

rapid onset of multiple and severe disabilities early in life, and gradual onset of a few mild-to-moderate disabilities later in life. The first pattern is termed “aging with disability” and the second “disability with aging.”

**Among people with major mobility limitations, more than one-fourth says they do not have a disability, and among wheel chair users 15-20% says they do not have a disability.**

The NHIS-D was the first large national survey to ask respondents about their *perceptions* of their disability—whether they themselves or other people *regard* them as having a disability. Iezzoni, McCarthy, Davis & Siebens (2000) investigated the relationship between the severity of lower extremity mobility limitations and perceptions of disability. They found that severity of the mobility limitation was the best predictor of perceived disability—the more severe the limitation, the more likely were respondents, both self and proxy respondents, to report that the sample person was perceived to have a disability. What is more remarkable, however, is that even among persons with major mobility limitations, substantial minorities do not regard themselves as having a disability; furthermore, even among those whose mobility limitation are most obvious to others—wheelchair users—a non-negligible minority did not regard themselves as having a disability or think that others so regarded them.

**Although some direct linking data were missing, researchers were able to use indirect information to link survey data for mothers and their children, making it possible to study the relationship of children's disability and mothers' mental health.**

A common problem in analyzing surveys is missing data—data that should have been recorded but was not. One approach to missing data is to “impute” values for the missing data based on known information related to the missing values. In a study by Witt, Riley, and Kasper (2003), the investigators needed to link information for a mother to information about her child. A code linking mother and child was supposed to have been recorded by interviewers, but in an unacceptably high proportion of cases it was not recorded. However, the researchers reasoned that if there were one woman in the child’s family between the ages of 18 and 56 years, it probably was the mother, and if there were more than one woman in that age range, the oldest was probably the mother. They validated that selection algorithm with the already linked children and mothers, making a correct match in 99.7% of the cases. They then used the algorithm to match children to mothers in cases where the interviewer had not recorded the linking information.

## C. ASSISTIVE TECHNOLOGY AND PERSONAL ASSISTANCE

### ASSISTIVE TECHNOLOGY

**The number of persons using wheelchairs more than doubled between 1980 and 1994, and only a small part of the increase was due to the aging of the population.**

The NHIS-D asked about use of a long (but not exhaustive) list of devices used by persons with disabilities to assist functioning. With data from the 1994 NHIS-D, Phase 1, Russell, Hendershot, LeClere, Howie, and Adler (1997) estimated the prevalence of assistive devices by age. The general category of device most widely used was mobility (7.4 million), followed by anatomical (mostly braces), hearing, and vision. The most common specific assistive device was crutches followed by hearing aids and back braces. For some mobility assistive devices, similar questions been asked in earlier years of the NHIS, allowing a limited study of trends for those devices. For all mobility devices except crutches, there were substantial increases in use between 1980 and 1994. In part the increases resulted from rapid growth in the population of elderly persons, who are heavy users of mobility devices. However, even with controls for age, there was rapid growth in use of mobility assistive devices between 1980 and 1994.

**About 1.7 million persons use wheelchairs; most are elderly but 88,000 are under the age of 18. About 40% of wheelchair users have architectural barriers in their homes, and about 80% report that their public transportation system is difficult to use.**

The most common type of assistive technology is for mobility limitations, and wheelchairs are one of the most common mobility assistive devices. Kaye, Kang, and LaPlante (2000, 2002) have published an extensive set of statistics on the prevalence of mobility assistive devices and the characteristics and circumstances of their users, with a particular emphasis on wheelchair users. Despite improvements in accessibility in the U.S., especially since the passage of the Americans with Disabilities Act, the researchers find that many wheelchair users continue to encounter barriers in their daily lives, such as steps to enter their homes, steps inside the home, doors that are difficult to open, cupboards that are difficult to reach, and public transportation systems that are difficult to use.

## PERSONAL ASSISTANCE

**More than 14 million adults with disabilities get help with personal care or home management activities, and about three-fourths of the helpers are unpaid family members.**

The NHIS-D asked an extensive series of questions about receipt of personal assistance for personal care and home management by persons with disabilities, including the activity for which assistance was received, the identity of the person giving assistance, the number of hours of assistance, the adequacy of the assistance, and more. Kennedy and Walls (1999) used those data to describe some major features of personal care assistance in the U.S.: most care is given by a single person, usually the spouse or an adult daughter, and is unpaid; on average care is given on about 8 days in a two week period, and 4-5 hours of care are given on each of those days.

**One million adults with disabilities do not get the help they need with bathing, dressing, and other personal care activities, and those not getting care are disproportionately poor, minorities, and living alone.**

Among the NHIS-D questions asked about personal assistance with activities of personal care or home management was whether or not the assistance met the need for assistance in the activity. In an analysis of unmet need, Kennedy (2001) found that 10-20% (depending on the activity) of persons with a need for assistance have assistance needs that are not fully met, more than 3 million people. For about 2 million of those people, the unmet need is in home management activities (shopping, preparing meals, etc.), but for nearly a million the unmet need is in personal care activities (bathing, eating, etc.) Furthermore, those with unmet need are disproportionately people at risk—poor, minorities, living alone.

**People whose need for help with personal care is not met are more likely than others to suffer falls, burns, weight loss, pain, and dehydration.**

What are the consequences if people with disabilities have a need for assistance with personal care (bathing, eating, toileting, etc.) that is not met? LaPlante, Kaye, Kang, and Harrington (2004) analyzed NHIS-D, Phase 2 data to answer that question. They found that although most persons with disabilities (more than 90%) have their needs for personal care assistance met, those with unmet need are much more likely to be dissatisfied with their care and to suffer adverse health outcomes, such as falls, burns, weight loss, pain, and dehydration.

**Among adults with disabilities who need help with personal care or home management, having health insurance coverage increases the probability of getting some care but not the probability of getting adequate care.**

Lima and Allen (2001) used data from the NHIS-D, Phase 2, to compare two groups of adults who need help with one or more personal care or home management activities: those who received no help and those who received inadequate help. They compared each of those groups to persons whose need for help was adequately met. They found that people with no help or inadequate help both differ from those with adequate help, but in different ways: those who get no care tend to be unmarried, living alone, and without health insurance; those who get inadequate care tend to be relatively young and women. Both groups were disproportionately from minority populations. The authors note that current trends in population growth, marital patterns, and living arrangements will tend to increase the relative size of populations that now receive no help or inadequate help with their personal care and home management needs.

## RELATIONSHIP OF ASSISTIVE TECHNOLOGY AND PERSONAL ASSISTANCE

**Among elders with disabilities in personal care or home management, greater severity leads to more use of personal assistance or special equipment; if only one of these is used, it tends to be special equipment.**

Need for assistance in a personal care or home management activity may be met either by help from another person or by use of an assistive device. Because personal assistance and assistive devices differ in cost and effect on independence, it is important to know the factors associated with each type of assistance. Verbrugge and Sevak (2002) used data from the NHIS-D, Phase 2, to study those factors. They found that severity of disability and general health/disability are important: people with severe disabilities and poor general health/disability tend to use both personal assistance and assistive devices; using personal assistance only is associated with poor general health/disability; and using assistive devices only is associated with severe disability. They also found that among people with the same health/disability status and severity, assistive devices are more likely than personal assistance to reduce the difficulty of an activity.

**Adults with mobility limitations who use canes and crutches use less mobility personal assistance than adults who used walkers, wheel chairs, or no mobility devices. Canes and crutches are low cost, versatile aids that can partially substitute for human assistance by reducing the overall number of hours of care required.**

In two papers based on the same analyses of the NHIS-D, Phase 2, Allen and colleagues (Allen, Foster, & Berg, 2001; Allen, 2001) investigated the interplay of human assistance and use of assistive devices among adults with mobility limitations. They found that adults with mobility limitations who used canes and crutches used less personal assistance than their counterparts who used other mobility assistive devices or no mobility devices. Because canes and crutches are generally inexpensive compared to other types of mobility devices and personal assistance, the authors suggest that these “low technology” devices are a cost-effective means of maintaining the mobility-dependence of persons with mobility limitations.

**Among persons over 50 with mobility limitations, about one-third use neither mobility aids nor personal assistance, another third use mobility aids only, and the rest use the personal assistance, with or without mobility aids.**

Agree, Freedman, and Sengupta (2004) studied patterns of use of personal assistance and assistive devices among persons over 50 years of age with mobility limitations. About equal numbers in this group use no assistance, assistive devices only, and personal assistance (alone or in combination with assistive devices). Severity of disability is an important determinant of use patterns: if the severity of the disability is low, most persons with mobility limitations use only assistive devices; but if severity is high, both assistive devices and personal assistance are likely to be used. Younger age and a cognitive limitation also associated with the use of both types of assistance.

**Among adults with limitations in bathing, walking, transferring, or getting outside, users of assistive devices only are more likely than users of personal assistance to report residual difficulty (pain, fatigue, time use) in those activities.**

Agree and Freedman (2003) investigated the effectiveness of personal assistance and assistive devices, where effectiveness was measured by whether or not an activity took a long time to do, was painful, or was tiring. The study population was adults who reported difficulty, when unassisted, in the personal care activities bathing, transferring, walking, or getting outside. It was found that adults who used only assistive technology were more likely to report that each of the personal care activities was time consuming, painful, or tiring than were adults who used personal care, either alone or combination with assistive technology. However, adults who used only assistive devices were less likely than others to report that they had an unmet need for personal assistance.

#### d. DISABILITY POLICY

##### THE COST OF DISABILITY

In formulating and debating disability policy, cost is almost always an important consideration: what will it cost to implement a new policy? Will those new costs be offset by savings induced by the policy? While the NHIS-D itself does not include very much information about the costs of programs and services, investigators have successfully combined disability prevalence estimates from the NHIS-D with cost estimates from other sources to estimate costs of various disabilities.

**The lifetime costs per person of developmental disabilities (above normal costs) are \$1.0 million for mental retardation, \$0.9 million for cerebral palsy, \$0.6 million for vision impairment, and \$0.4 million for hearing loss. Four-fifths of the lifetime costs are due to loss of productivity (*versus* direct program costs).**

Honeycutt and colleagues (Honeycutt et al., 2003; Honeycutt et al., 2004) used data from the NHIS-D on prevalence of disabilities and use of health care services together with data on costs from other sources, to estimate the lifetime costs of four disabilities—mental retardation, cerebral palsy, vision impairment, and hearing loss. The high cost of these disabilities to society is offered as a justification for continuing and expanding programs to prevent developmental disabilities and the secondary disabilities that often ensue.

**The lifetime, per person cost to society of prelingual deafness is about \$1 million, including direct costs (such as special education) and indirect costs (such as lower economic productivity).**

Mohr, Feldman, and Dunbar (2000) used NHIS-D data and data from other sources to estimate the lifetime costs of severe to profound hearing loss. They estimate the lifetime cost, both direct (e.g., special education) and indirect (lower productivity), at \$297,000. For persons who are deaf from birth or before they learn to talk, the lifetime cost is much more, about \$1 million. The authors suggest that these figures support policies and programs for early childhood detection and intervention.

**About 13 million adults with disabilities receive an average 31 hours per week of help with personal care and home management, worth about \$200 billion per year, 85% of which is unpaid help.**

The NHIS-D, Phase 2, included questions on personal assistance received by persons with limitations in personal care and home management activities. The questions covered the relationship between the person and the care provider, whether the care was paid or unpaid, and the number of hours of care provided. LaPlante, Harrington, and Kang (2002) used these data to estimate the number of hours of paid and unpaid care given. Using data on cost of personal care services from other sources, the researchers then estimated the dollar value of the services provided at about \$200 billion per year, the vast majority of which was unpaid help from family members and friends. Because of declining fertility, there will be a future decline in the average number of adult children available to provide free care for their parents.

## EMPLOYMENT POLICY

**Among working age adults with disabilities, more than half are not working. The disability-causing conditions most likely to prevent work are cardiovascular, respiratory, and sensory (vision and hearing).**

Using Phase 1 of the NHIS-D, Zwerling and colleagues (Zwerling et al., 2002) estimated employment rates and their correlates for adults with disabilities, defined as limitations in personal care activities, home management activities, or physical activities. They found that employment rates are low for all subgroups of people with disabilities, but they are especially low for people who are African American and have not completed high school. The researchers also studied the type of medical condition reported to be the cause of disability, and found that the conditions most strongly related to not working were cardiovascular conditions, respiratory conditions, sensory conditions (seeing and hearing), schizophrenia, and paranoid/delusional disorders.

**Among young adults with disabilities, those with earlier onset are less likely to be employed than those with later onset, partly because they are less likely to have completed high school.**

**Among young adults with disabilities, those who were better educated and in good health were more likely to be employed. SSI recipients were less likely to be employed. Participation in vocational rehabilitation was not related to employment.**

Two reports have focused on employment outcomes for younger persons with disabilities. Loprest and Maag (2003) used the NHIS-D, Phase 2, to study the direct and indirect effects of disability on employment. They hypothesized that early onset of disability (before age 22) would tend to interfere with the attainment of higher levels of education; and because lower educational attainment tends to reduce employment opportunities, early onset of disability indirectly reduces employment by lowering

educational attainment. The indirect effect would be in addition to the direct effect of a disability on employment. The researchers tested this hypothesis on two cohorts, aged 22-35 and 44-54. The hypothesis was confirmed for the younger cohort but not for the older cohort. The authors suggest that efforts to increase the employment rates of younger persons with early onset of disability should include an emphasis on education.

In the other study of employment outcomes for younger persons with disabilities, Berry (2000) examined factors associated with being employed or not in the two weeks before interview for persons in the “transition ages” of 18-29 years who had limitations in activities of daily living or instrumental activities of daily living. Berry was particularly interested in the effects on employment of participating in two government programs for persons with disabilities, Supplemental Security Income and Vocational Rehabilitation. Like Loprest and Maag (2003), Berry found that transition age persons with disabilities were more likely to be employed if they were well educated; however, participation in vocational rehabilitation was not related to employment, and receipt of Supplemental Security Income was negatively related to employment—receiving SSI (and the Medicaid benefits that accompany SSI) are a deterrent to working.

**Applicants for work disability income benefits are much less likely than those who receive benefits to have a disability, and applicants who do have disabilities have fewer disabilities than do beneficiaries.**

Social Security Disability Income (SSDI) provides income to persons unable to work because of a disability. It has been suggested that the cost of the SSDI program might be reduced if workers with disabilities were given vocational assistance before they qualified for SSDI, enabling them to stay on the job. To learn more about such workers, Kennedy and Olney (2002) used the NHIS-D, Phase 2, to compare SSDI applicants with SSDI beneficiaries. They found that only about one-half of applicants have disabilities and those who do have disabilities have fewer than beneficiaries. Furthermore, very few of the applicants say that they need additional vocational services. The authors suggest that without further screening, applicants are not a good target population for early intervention services to prevent SSDI enrollment—they are not likely to qualify for SSDI anyway, and they do not seem to need services.

**Most people with mental retardation who are receiving vocational rehabilitation services are employed, but most are in noncompetitive, segregated work settings.**

**Among adults with disabilities who receive vocational services, African Americans and Hispanics are much less likely than non-Hispanic whites to be placed in competitive jobs.**

Vocational rehabilitation (VR) services are intended to enable persons with disabilities to secure or retain paying jobs, preferably in the competitive labor market rather than in segregated, “sheltered workshop” settings. In two articles, Olney and Kennedy (2001, 2002) investigated outcomes of VR participation for two subgroups of



persons with disabilities who are at high-risk: persons who are mentally retarded and persons in minority groups (African American and Hispanic). While substantial numbers in both groups were placed in paying jobs, they were much less likely than the comparison groups of VR participants (those without mental retardation or those not in minority groups) to have a competitive job. The authors suggest that institutional bias in the VR system and the labor market accounts for the differences in outcomes.

**Nearly one-tenth of all adults with disabilities who were in the workforce during the 5-year period immediately following passage of the ADA experienced some form of job discrimination.**

A cornerstone of disability employment policy is the Americans with Disabilities Act (ADA) that forbids discrimination against workers based on disability. The ADA became law in 1990 and the NHIS-D, Phase 2 was fielded about 5 years later. To evaluate the effects of ADA, adults with disabilities who had worked in the past 5 years were asked about discrimination in hiring, promotion, training, transfers, and job loss. Kennedy and Olney (2001) analyzed those data and found that nearly 1-in-10 workers reported some form of job discrimination based on disability. The authors speculate that the actual figure may be higher, because many workers, especially older workers, are not yet aware of their rights under ADA, a speculation supported by the finding that younger workers are more likely to report job discrimination. The authors suggest a number of steps that might be taken to reduce employment discrimination based on disability.

**Among adult workers with disabilities, about 16% need an accommodation to work; workers with physical conditions are more likely to be accommodated than workers with mental conditions.**

The Americans with Disabilities Act requires that employers make reasonable accommodations for employees with disabilities. The NHIS-D, Phase 2, included questions about the accommodations that persons with disabilities need in order to work, and the accommodations that they actually get. The questions covered a variety of accommodations, from architectural features such as ramps to organizational features such as flexible work schedules. Zwerling and his colleagues (Zwerling et al., 2003) analyzed the data and found that 16% of workers with disabilities need an accommodation in order to work, and 12% receive an accommodation. The most frequent accommodations were accessible transportation, elevators, and modifications to work stations. Workers with mental health problems or psychiatric conditions were less likely than workers with other disabilities to receive accommodations.

**One-third of “work-oriented” adults with disabilities need some kind of job accommodation in order to be able to work. Among non-working, non-retired disabled adults who could work if accommodated, more than half say they have difficulty searching for a job, most often because they believe that no appropriate jobs are available.**

In two papers, Loprest and Maag (2001, 2003) the NHIS-D, Phase 2, to studied work barriers for adults with disabilities who were “work-oriented.” Work-oriented adults are not working but willing and able to work (with accommodations if needed). Nearly one-fourth of adults with disabilities are work-oriented, and might become employed if barriers to work were removed. Loprest and Maag considered three types of barriers and accommodations: workplace accommodations, job search, and transportation. They found that few work-oriented adults with disabilities use para-transit or public transportation, and their reasons for not using them are not related to health or disability, suggesting that transportation problems are not an important deterrent to employment. They did, however, find that most of the work-oriented persons had had problems searching for work and about one-third need a workplace accommodation.

**Among persons with arthritis, the odds of working are higher for those who are younger, have little difficulty lifting 10 pounds, and have some college education.**

Milidonis and Greene (2005) studied the work status of non-retired adults with arthritis in an attempt to identify factors associated with working in this population. Based on previous studies, they expected to find that persons reporting a lot of pain associated with their arthritis would be less likely to be working than those who reported little pain, but they found that in the NHIS-D data, pain and work status were not related. The variables they found to be related to working among arthritis patients were relatively young age, college education, and the absence of limitation in lifting objects.

#### PUBLIC HEALTH POLICY

**Doctors have prescribed drugs for nearly two-thirds of adults with disabilities, but many of them (1.8 million) do not take the drugs as prescribed because of their high cost.**

**Compared to other adults with disabilities, adults with psychiatric conditions are more likely to give cost as a reason for not complying with a prescribed drug regimen.**

The NHIS-D, Phase 2 data were used in two papers by Kennedy and colleagues (Kennedy & Erb, 2002; Kennedy & Sclar, 2003) to investigate prescription drug use by adults with disabilities. They found that drugs had been prescribed for most (70%) adults with disabilities, but many (12% of those with prescriptions) did not take their medicine as prescribed, often because they could not afford to. While persons with all types of disability face this problem, the problem is greater among those with mental health problems than others. About half of persons who do not comply with their prescriptions report suffering health consequences. The rate of cost-related prescription noncompliance is higher among younger persons who are not eligible for Medicare and would not benefit from the wider drug coverage in that system some policy makers have advocated.

**Adults with disabilities, especially walking disabilities, are much more likely than other adults to be obese, but not more likely to have attempted weight loss or been counseled by a doctor to lose weight.**

Obesity is a leading cause of preventable deaths, and reduction of the prevalence of obesity is a major objective of public health policy. A study by Weil et al. (2002) used the NHIS-D, Phase 2, to examine obesity and its prevention among adults with disabilities. They found that one-fourth of adults with disabilities were obese compared to one-seventh of adults without disabilities. Controlling for other factors related to obesity, they found that adults with disabilities had twice the risk of obesity. While the risk of obesity was high for all types of disability considered, it was especially high for people with lower extremity problems, who were about 2.5 times more likely than those without disabilities to be obese. Despite the high prevalence of obesity among persons with disabilities, they are no more likely than people without disability to have attempted to lose weight or to have been advised by a health professional to lose weight.

**Wheel chair users whose homes have accommodations (e.g., widened doorways) are less like to have injurious falls.**

Berg, Hines, and Allen (2002) used data from NHIS-D, Phase 2, to study the relationship between home accessibility features and injurious falls in the 12 months before interview among adult wheelchair users. Overall, about 40% of wheelchair users had fallen, and about 20% had had an injury-causing fall. The home accessibility features considered were bathroom modifications, widened doors or hallways, easy-open doors, kitchen modifications, and hand rails. Persons who had none of those features were about 10 times more likely than those who had all five to have had an injury-causing fall. If the home had any of the accessibility features, the risk of a fall was reduced by about one-half. The authors suggest that health care insurance, public and private, should cover home accessibility features as a means of reducing the incidence of injurious falls, and that barrier-free universal design principles be adopted in residential architecture.

**About 5.6 million persons have a disability that resulted from an injury, more than 1/4 of all persons with disabilities; the most common cause of the injury was a motor vehicle collision.**

**About 1.2 million U.S. adults have a disability resulting from a motor vehicle crash, with the highest prevalence in mid-life (35-64). About half of those of working age could not work because of their disability.**

Two studies using the NHIS-D have focused on injury and disability, Shults and others (2004) and Guerrero, Sniezek, and Sehgal (1999). In the NHIS-D many questions were asked to identify specific types of disability. When a disability was identified, the respondent was asked to name the main cause of the disability, whether it resulted from and injury, and if so, the environmental cause of the injury. Those data from the 1994 NHIS-D were used by Guerrero, Sniezek, and Sehgal, to estimate the number of disabilities resulting from injuries. They found that about 5.6 million people reported

disabilities caused by injuries, or 27% of all persons with disabilities. About one-third of all persons limited in activities of daily living, instrumental activities of daily living, or function (walking, lifting, grasping, etc.) were limited by a condition caused by an injury. The most common causes of injuries were motor vehicle crashes and falls. These statistics demonstrate that injury prevention should be an important part of public health policy on disability.

In the second study of injury-related disability, Shults and others focused on disability attributable to automobile crashes. They used the same approach as Guerrero, Sniezek, and Sehgal, but with the 1995 NHIS-Data. They found that about 1.2 million adults had disabilities resulting from automobile crashes, and the prevalence rate was highest in the age group 35-44. Most of the crash-related disabilities had occurred more than five years before interview, and about 40% of the persons affected were unable to work because of their disability. The authors point out that because crash-related disability occurs relatively early in life, its effects are long-lasting, and create a substantial burden on both individuals and the public.

#### e. POPULATIONS OF SPECIAL INTEREST

##### CHILDREN

##### Prevalence

In the section on “New Methods for Defining Disability” above, the work of several groups of researchers on child disability were reviewed (Newacheck et al., 1998; Stein & Silver, 1999; Stein & Silver, 2002; Hogan, Msall, Rogers, & Avery, 1997; Benedict & Farel, 2003). In addition to developing new measures of child disability, those researchers reported estimates of the prevalence of child disability based on their definitions. Because their definitions were developed with different applications in mind, it is not surprising that their estimates of prevalence also differ.

##### **The prevalence of childhood disability is greater among boys, African-Americans, and children from low-income and single-parent households.**

Newacheck’s work (Newacheck *et al.*, 1998) not only estimates prevalence of disability (“special health care needs”) among children, it examines social and demographic correlates of differences in prevalence, and differences in health and health care according to disability. Children with disabilities tend to have poorer health, less access to health care and less use of health care services.

##### **As measured by performance of specific age-appropriate tasks, 3.3% of children aged 4-6 years have developmental delays, but only 1/3 of their mothers say the child has a developmental delay.**

The work by Simpson, Colpe, and Greenspan (2003) was in part methodological: they developed questions NHIS-D survey questions based on the Functional Developmental Growth Chart Questionnaire (FDQ) to measure disability in infant and pre-school children (4-59

months). The FDQ questions asked parent-respondents to report whether or not the sample child had developed selected functions appropriate to their age and sex. Using normative responses established in other studies, the responses of parents were used to identify children with developmental delays. The parents were also asked several more general and conventional questions about whether or not their children had a developmental delay. While the overall prevalence estimates for developmental delay were similar using the two measurement approaches (about 3.4 percent), the overlap between the groups identified by the two approaches was relatively low—only about one-third. That is, many children with delays, as measured by developmental milestones, were not identified by their parents as having a delay, and *vice versa*. These results indicate the difficulty of measuring disability in young children using survey methods

### **Services: Met and Unmet Need**

**About 9% of children use "special" services for health, education, or mental health, and about one-third of them use more than one type of special service, creating a need for coordination among the different service systems.**

Stein and Silver (2003) studied use of non-routine, specialized medical, educational, and mental health services among children and youth under the age of 18 years. Overall, about 9.6% of children used such services, with medical services being most used (5.5%), followed by educational services (5.0%) and mental health services (1.5%). Compared to nonusers of these services, users were more likely to be male, white, and poor, patterns that correspond to differences in the prevalence of chronic conditions. Among children who receive any of these special services, many (about one-third) receive more than one type, suggesting that integration of services may be an issue.

**Among children who receive medical attention for a diagnosed condition, nearly half have a disability and more than 1 in 5 have a major disability.**

Msall and others (2003) investigated the relationship between children's medically-attended chronic conditions and functionally-defined disability in four domains: mobility, self-care, communication, and learning-behavior. They summarized medically-attended chronic conditions into three categories: physical, neuro-developmental, and learning-behavioral disorders. Functional disability was most common among children with learning-behavioral conditions (88%), followed by neuro-developmental conditions (61%) and physical conditions (32%). The authors argue that for a full understanding of disability among children and youth, information is needed on both medical diagnoses and functional limitations.

**Most children with disabilities receive the supportive health services (e.g., speech therapy, respiration therapy) they need, but there is substantial unmet need in low income families.**

“Supportive services” include services that provide home health care or assist the family with a disabled child's development, speaking or hearing, or daily activities. They

differ from traditional medical care, such as doctor visits, in being more commonly used by children with disabilities and in being used continuously over long periods of time. Because they are sometimes overlooked in studies of child health care, Maag (2000) focused on them, using the 1994-1995 NHIS-D data on children. To define disability, Maag used a slightly modified version of the definition developed by Hogan, et al. (1997). Maag found that the supportive services needs of most children with disabilities were being met, but children from families at or below the poverty line were more likely to have unmet needs for supportive services than children from non-poor families (9.3% *vs.* 6.9%).

**Regardless of income level, children with disabilities are more likely than their healthy peers to have unmet needs for medical care, mental health services, prescription medicine, and eyeglasses.**

Silver and Stein (2001) used the 1994 NHIS-D to study child disability and unmet need for four health care services (dental care, prescription medicine, eyeglasses, and mental health services). Disability was measured by the method developed earlier by Stein and Silver (1999). Factors affecting accessibility of health care services—family income, insurance and having a regular care provider--were also included in the analysis. It was found that children with disabilities were more likely than other children to have health insurance and a regular care provider; nevertheless, they were more likely to have unmet needs for health care services. Although the disparity in unmet need was not large, it was persistent across types of need and family income levels.

**Among school-aged children with disabilities, 11.5% have emotional or behavioral disorders, but only about two-fifths of those children receive mental health services.**

Witt, Kasper, and Riley (2003) studied unmet need for mental health services among children with disabilities and poor psychological adjustment. Children were classified as having a disability if they were eligible for Phase 2 of the NHIS-D; that is, they had one or more of the characteristics used to define the Phase 2 target population. Psychological adjustment was measured using the PARS scale (Psychological Adjustment and Role Skills), with “poor adjustment” defined as a score more than a standard deviation below the mean. Children with poor psychological adjustment (11.5% of all children in the sample) were assumed to need mental health services; however, only 41.8% of those children received mental health services. If health professionals were actively involved in coordinating care for the child (rather than just the family—or no one), mental health service needs were somewhat more likely to be met.

**Only about one-fifth of children with mental, emotional, or behavioral problems regularly see a psychologist or other mental health care professional.**

In a general study of school-age children with mental, emotional, or behavioral problems, Colpe (2001) included a measure of the utilization of mental health services—

whether or not the child was currently seeing a provider of such services. Colpe suggests that all children with mental, emotional, or behavioral problems could benefit from mental health services, but she found that only 19.2 percent of them were actually receiving those services.

### **Insurance**

#### **Uninsured children with disabilities are four times more likely than their insured counterparts to have unmet needs for medical, mental, dental, and pharmacological services.**

Using the federal Maternal and Child Health Bureau definition of children with special health care needs, Newacheck and others (2000) found that about 18% of children (age 17 years and under) had such needs. Most were covered by health insurance, but about 11% were not. Those who were not covered were less likely to have a usual place of medical care and a regular clinician; they were also more likely to have unmet needs for medical care, dental care, prescriptions, eyeglasses, and mental health care.

#### **Insurance coverage is not related to the prevalence of unmet need for supportive services among children with disabilities.**

“Supportive services” include services that provide home health care or assist the family with a disabled child’s development, speaking or hearing, or daily activities. Maag (2003) found that health insurance coverage, public or private, was not significantly related to the probability of having an unmet need for supportive services among children with disabilities; that is, disabled children with insurance were as likely as those without insurance to have an unmet need. This is surprising, perhaps, because a large body of literature has demonstrated that insurance coverage is related to other measures of the accessibility of health care to children with special health care needs (e.g., Newacheck and others, 2000). Because supportive services are especially important for children with disabilities, the lack of an “insurance effect” has an important policy implication: as insurance coverage is currently structured, increasing the number of children covered may not be the best approach to meeting the needs of children with disabilities.

#### **Children enrolled in the Florida Child Health Insurance Program are twice as likely to have chronic conditions as children eligible for the program, indicating selective enrollment and potential costs greater than anticipated.**

A study by Stein RE, Shenkman E, Wegener DH, and Silver EJ (2003) illustrates a somewhat unusual use of the NHIS-D and also reaches some important policy conclusions. Stein and colleagues compared data from a survey of children enrolled in Florida’s version of the State Child Health Insurance Program (SCHIP) with data on a subset of NHIS-D sample children selected to match the eligibility criteria for the Florida program. SCHIP was designed on the assumption that enrolled children would be broadly representative of all eligible children with respect to health care needs, but some observers feared that the program would disproportionately attract children with expensive special health care needs, driving up the cost

of the program. The study by Stein and others was designed to test that hypothesis. They did, in fact, find that children in the Florida SCHIP program were about twice as likely to have chronic conditions and various sequelae of chronic conditions as the comparison group from the NHIS-D sample. The authors conclude: "If replicated in other SCHIP programs, these findings raise questions about the basic underlying assumptions concerning the health of potential enrollees and could have implications for the long- term fiscal viability of the program."

### **Risk Factors**

#### **Children with disabilities often live in families with lower income and unhealthier environments, putting them at risk of additional developmental difficulties.**

Hogan DP, Rogers ML, Msall ME (2000) examined some aspects of the environments, social and physical, of children with functional limitations in mobility, self care, communication, or learning. They found that functionally limited children were more likely than others to live in families with one parent, low income, and low educational attainment; also, they were substantially more likely to be exposed to second-hand smoke. There were no differences, however, with respect to the presence of handguns or smoke detectors in the households of children with and without disabilities. The authors suggest that the social and physical environments of children with disabilities may place them at elevated risk of some adverse health outcomes.

#### **Minority children with disabilities are less likely than other children with disabilities to visit a doctor and less likely to have a regular place to get medical care.**

#### **Among children with disabilities, NonHispanic black children and children from families with relative little education are less likely to use a variety of health-related services.**

Several studies that used NHIS-D included measures of ethnicity or race and found differences associated with those variables, often to the disadvantage of minority populations. Because race or ethnicity was not a central feature of some of those studies, they have been discussed elsewhere in this report. Two studies of children that did make race a more prominent part of the analysis are discussed here.

Newacheck PW, Hung YY, Wright KK (2002) found that among children with special health care needs, a greater proportion of minority children than other children report limited health care access, such as not having a usual place of care, having a usual place of care that was not a doctor's office, not having evening hours at a usual place of care, or being dissatisfied with some aspect of care received at a usual place of care. Access to care was more restricted for Hispanic children than for African American children. Multivariate statistical controls for possible confounding variables reduced, but did not eliminate, the gaps in access to care according to minority status.



Weller WE, Minkovitz CS, Anderson GF (2003), in a general study of the characteristics and health care of children with special health care needs, found that race and ethnicity was related to use of health care services, with minorities usually being somewhat disadvantaged.

### **Effect on families**

**Parents of children with poor health or disabilities, both mothers and fathers, are less likely to be employed than other parents.**

**Parents of children with disabilities are less likely to be employed, less likely to have employer-provided health care insurance, and more likely to depend on publicly funded health care.**

**In families with children who have disabilities, more than one-third parents have made employment accommodations in order to care for their children.**

Several studies have examined the relationship between child disability and employment of the child's parents. Kulthau and Perrin (2001) used the 1994 NHIS-D on children to analyze the effects on employment of child disability (limitation in play or school activity) and several measures of child health. After statistically controlling for possible confounding variables, they found that both poor health and disability were related to lower rates of employment for mothers and fathers. The relative odds of employment of fathers and mothers of children with disabilities were 0.66 and 0.75, respectively.

This finding was supported by another study (Heck and Makuc, 2000) using the same data set but different measures of disability and employment. The parents of children with special health care needs were less likely than other parents to be employed full time, even with statistical controls for possible confounding variables. Because most working persons obtain private health insurance coverage through their employer, it is not surprising that the same study found that the parents of children with special health care needs were less likely to have private health care insurance; but the lack of private coverage was made up by Medicaid coverage.

Another researcher used data from the 1994-1995 Phase 2 child questionnaire, to study the employment consequences of parenting a child with a disability. Anderson (2002) found that in about 30% of families of children with disabilities, someone was reported to have made one or more job accommodations as a result of the child's disability, including not getting a job, quitting a job, changing jobs, refusing a better job, or changing work hours. The rates of job accommodation were higher in families that had a child with intellectual or developmental disability than in families that had children with other disabilities.

**The impact on a family's sleep, work, and finances of having a child with a disability is greater if the child needs medical care or multiple therapies.**

In the set of eight questions on family impact used by Anderson, most questions (6) dealt with work, but there was one question on sleep loss and another on financial hardship. Neely-Barnes and Marcenko (2004) combined responses to all eight questions to form a summary index of family impact with values from 0 to 3, scoring 1 point for any work accommodation, 1 point for sleep loss, and 1 point for financial hardship. In a multivariate analysis that controlled for potential confounding variables, they found that families whose children needed medical care or multiple types of therapy had higher family impact scores. The authors suggest that when a child needs medical care and therapy, parents are required to spend more time tending to those needs, which creates additional stress on them and their families.

**Among school-aged children with disabilities, family stressors --work loss, finances, and sleep loss--are better predictors of poor child adjustment than the disability itself.**

Witt, Riley, and Coiro (2003) investigated the effect of family stressors on the psychological adjustment of children, as measured by the Personal Adjustment and Role Skills (PARS) scale, the items for which were included in the NHIS-D questionnaire. Family stress was measured by the eight questions on family impact used by Anderson (2002) and Neely-Barnes and Marcenko (2004). Other variables included in the analysis were family income; the number of parents; the mother's health, disability, and distress or depression; and the child's age, race, sex, health, and type of disability. They found that in families experiencing stress related to the disability of a child, children were about twice as likely (compared to children in stress-free families) to have low PARS scores (more than one standard deviation below the mean score). The authors interpret the relationship as causal—the family stress caused by parenting a child with a disability impedes the psychological adjustment of the child. They recommend that the medical community address the health needs of all family members in families with a disabled child.

**Children living in families with siblings who have disabilities are more likely than other children to have an overall health status that is less than "good," and to have unmet needs for eyeglasses, prescription medicine, or dental care.**

Does the stress experienced by families in which a child has a disability affect the health of family members other than the disabled child? This question was addressed directly by Hogan, Park, and Goldscheider (2003). They compared the health of children who did or did not have a sibling with a disability. Health was measured in several different ways, and possibly confounding variables were statistically controlled in their multivariate analyses. They found that children who had a sibling with a disability were significantly more likely to be in poor health, and the difference was not accounted for by factors related to both disability and health, such as family income. They speculate that parents who care for a child with disability may allocate fewer of their resources,

including time, to their other children, resulting in more frequent poor health outcomes in those children.

## WOMEN

**In general, women with disabilities are as likely to receive screening and preventive health care services as other women, but this is not true for some disabilities.**

**Women with disabilities are less likely than women without disabilities to be screened for cervical and breast cancer.**

Two studies have examined screening among women with disabilities. Iezzoni and others (2001) used the 1994-1995 NHIS-D and other NHIS data for those years to examine the prevalence of many different screening and preventive health care services among women without disabilities and women with a variety of disabilities. There were no consistent differences overall; that is, women with disabilities were more likely to receive some services and less likely to receive others, depending on the service and the type of disability. With respect to particular disabilities, however, there were some clear patterns: for instance, women with serious limitations in lower limb mobility were much less likely to be given a Pap test for cervical cancer (OR = 0.6) and a mammogram to detect breast cancer (OR = 0.7). Both women with disabilities and health care providers need to be educated about the importance of appropriate screening for health maintenance.

In the other study of screening of women, Nosek, Gill, and others (1998) focused on mammograms and Pap tests. They defined disability as being unable to perform one or more of the following tasks: lift 10 pounds; walk up 10 steps without resting; walk a quarter of a mile; stand for 20 minutes; bend down from a standing position; reach up over the head or reach out; use fingers to grasp or handle something; and hold a pen or pencil. In general, women with functional limitations were less likely to have been screened, only among older women with three or more limitations were the differences large and consistent.

## MINORITIES

**Native Americans are substantially more likely (30% or more) than other Americans to have a disability, even when factors frequently associated with disability are statistically controlled.**

Because the Native American population is relatively small, culturally diverse, and geographically dispersed, it is difficult to describe it statistically with survey data. The attempt was made, however, by Altman and Rasch (2003), using the combined 1994 and 1995 NHIS-D. The compared Native American adults with persons of other races—white, black, and other—with respect to several measures of disability: functional limitations of the upper and lower body, sensory limitations, limitations in activities of daily living and instrumental activities of daily

living, and limitation in major activity (e.g., work). Regardless of the measure of disability considered, Native Americans had significantly higher prevalence of disability; and while Native Americans have some characteristics independently associated with disability (e.g., low income, low education), statistically controlling those factors does not eliminate or even substantially reduce the gap in disability between Native Americans and other races.

## F. TYPE OF DISABILITY

### MOBILITY

**Among people with major mobility disabilities, the average age is 67 and one-third said their disability began at age 50 or before.**

Iezzoni and her colleagues have produced a series of papers on adults with lower extremity mobility difficulties. They used NHIS-D questions on the difficulty experienced in walking, climbing stairs, and standing, and questions on use of mobility assistive technology, to classify sample adults with respect to their mobility difficulty level: none, minor, moderate, or major. One of their papers (Iezzoni and others, 2001) was a general statistical description of the demographic and health characteristics of persons with lower extremity mobility difficulty. Among the findings they emphasize is that mobility difficulty, although more common in old age, often has its onset at relatively young ages; for instance, about 30% of adults with major mobility difficulties reported that the condition causing the difficulty began at age 40 or before. Also emphasized at the loss in quality of life associated with mobility difficulties; for instance, adults with mobility difficulties were 6-8 times more likely than other adults to report that they were frequently anxious or depressed.

**Applications for health insurance from people with mobility limitations are more likely to be turned down than applications from other persons, usually because of a pre-existing condition.**

Another study by the Iezzoni group (Iezzoni LI, McCarthy EP, Davis RB, Siebens H, 2003) investigated health insurance coverage and access to health care among adults with mobility problems, defined in the same way. In some ways, their results are encouraging: adults with mobility problems were as likely or more likely to have been covered by health insurance (although it was often Medicare or Medicaid rather than private coverage), and they were more likely to have a regular source of health care, which is often taken as an indicator of good access. There were some less favorable indicators of coverage and access, however: mobility-limited adults were more likely than other adults to report that an application for insurance had been denied, usually because of a pre-existing condition; and they were and more likely to report that they had gone without needed medical care in the year before interview. In neither case, however, were very many mobility-limited persons affected: very few had been denied insurance or gone without needed care.

**Women with lower extremity mobility disabilities are less likely than women without disabilities to be screened for breast cancer and cervical cancer.**

**Among adults with disabilities, those with severe mobility limitations were more likely to receive some disease prevention services (physical exams, immunizations) but less likely to receive others (mammograms, Pap tests).**

In another study Iezzoni and colleagues (Iezzoni LI, McCarthy EP, Davis RB, and Siebens H, 2000a) examined use of screening and preventive services among women with mobility problems. They find that overall the use of these services by women with mobility problems is not uniformly more or less than their use by other women; however, women with serious mobility problems were significantly less likely than other women—including those with lesser mobility problems—to receive Pap tests and mammograms. (In a later study, discussed in the section on women, they examined screening and preventive services for women with a wider range of disability types [Iezzoni LI, McCarthy EP, Davis RB, Harris-David L, O'Day B, 2001]).

Jones and Beatty (2003) also studied preventive service use by persons with mobility limitations. Their study used a measure of mobility very similar to that used by the Iezzoni group, but with three rather than four levels. Their list of preventive services was somewhat more inclusive, and they included men as well as women; however, they restricted the study population to persons of working age (18-64). The results are essentially the same as in the Iezzoni study: for some preventive services, working age adults with mobility limitations were more likely to be users, but for other services they were less likely. For women, as in the Iezzoni study, mobility limitation was associated with lower levels of Pap tests and mammograms.

**Although arthritis causes limitations in many activities, the disabilities tend to be mild or moderate, accommodated by special equipment, and not requiring personal assistance.**

Arthritis is one of the most prevalent of chronic conditions and its prevalence increases rapidly in old age. Although it may result in different types of disability, most often causes lower limb functions, such as standing, walking, and climbing stairs. Verbrugge and Juarez (2001) studied arthritis-related disability using the 1994-1995 NHIS-D, and found that although arthritis-related disability is widespread, compared to disability caused by other conditions, it tends to be less severe: it is less often accompanied by other disabilities, it has shorter duration, and it causes less personal difficulty. Probably as a result of its less severe effects, arthritis-related disability is less likely to require assistance, and if assistance is required it is more likely than other disability to be provided by inexpensive assistive technology rather than personal care.

## SENSORY

**Serious difficulty with vision and legal blindness were independently associated with increased odds of poorer function for each of the ADLs and IADLs, with greater impact on self-reported function for younger adults.**

**Although people with low vision have lower employment rates than sighted people, there are important differences within the population: among those who are relatively young and in good health, most are employed; it is those who are older and in poor health who are not.**

Only two NHIS-D studies focused on vision impairments. Using data from the 1995 NHIS-D, Swanson and McGwin (2004) compared the prevalence of limitations in six activities of daily living and six instrumental activities of daily living among persons who had no limitation in vision, serious limitation in vision, and legal blindness. For every activity limitation considered, persons with low vision or legal blindness were more likely than sighted persons to have a limitation. Stratification of the analysis by age revealed that the relationship of vision to limitations was greater among younger persons than among older persons.

In a lengthy monograph based on analyses of the NHIS-D data, Kirchner, Schmeidler, & Todorov (1999) described statistically many characteristics of persons with low vision and blindness. Of particular interest to them was employment status. They found that overall employment rates for persons with low vision were low; however, they discovered that for young persons in good health, employment rates were higher—a majority of the youngest and healthiest persons with low vision were employed. The authors emphasize that policies and programs to promote employment of persons with low vision must account for the variety of employment experience in that population.

**Two out of three Americans age 65 and older with hearing loss, and nine out of ten younger Americans with hearing loss, do not use hearing aids.**

The only report focused on hearing impairments was a short, but wide-ranging statistical description, which used data from the NHIS-D and other sources (O’Neil, 1999). It points out that the prevalence of hearing impairments increases with age and is higher for men than for women; interestingly, hearing loss is more prevalent in the white population than the black population. Most persons with hearing loss—80%—do not use hearing aids. Although there have been substantial improvements in hearing aid technology, the technology is expensive, and hearing aids are not covered by Medicare; this probably is a factor in the relatively low prevalence of hearing aids use.

**Persons with chronic dizziness or imbalance are at least twice as likely to receive medical treatment for depression, supporting a hypothesis that both conditions have a common neurophysiological cause.**

**More than 3 million adults have a problem with their sense of smell (2.7 million) or taste (1.1 million) or both (0.6 million), about 40% of whom are over age 65.**

One of the sponsors of the NHIS-D was the National Institute on Deafness and other Communications Disorders, which includes in its portfolio disorders in balance, smell, and taste. For that reason some questions on those disorders were included in the questionnaire. The questions on balance were used by Baker, Ko, and Graubard (2003) to study the relationship between balance problems and medically-diagnosed psychological depression. Although it had been known that dizziness and depression can be caused by the same neurophysiological mechanism, previous studies of small and nonrepresentative populations had not been able to demonstrate a population effect. However, the authors find that dizziness and depression are

significantly related in the NHIS-D data, the first time the relationship has been found in a population-based study.

The questions on smell and taste disorders were used by Hoffman, Ishii, and MacTurk (1998) to estimate the prevalence and correlates of those conditions. They found that 2.7 million Americans report smell disorders (e.g., inability to detect odors) and 1.1 million reported taste disorders (e.g., inability to taste salt). Both disorders increase exponentially with age and both are related to other sensory limitations—sight and hearing. While chemosensory disorders (taste and smell) are not life-threatening, they are an important quality of life issue for many older adults.

## MENTAL

**Mental or emotional problems affect 5-10% of the adult population, and are frequently associated with limitations in personal care, home management, and work.**

Willis and others (2000) used Phase 1 of the 1994 NHIS-D to identify the population of adults with mental or emotional problems and describe their major socioeconomic characteristics. Using an inclusive definition, they estimated that 10% of adults had a mental or emotional problem; however, using the more conservative definition that the authors recommend, they estimate that 4.9% of adults have a mental or emotional problem. Under the conservative definition, a person was classified as having a problem if they reported a diagnosis of a serious disorder, had symptoms that seriously interfered with major activities, or used of medications for mental or emotional disorders. Persons with mental or emotional problems, defined in this way, were much more likely than others to report limitations in activities of personal care, home management, and work. For instance, among adults with mental or emotional problems more than 40% reported they were limited in their ability to find or keep a job, compared to only 5% among adults without such conditions.

**Serious mental illness is more strongly related than physical disability to unemployment, application for disability benefits, and receipt of disability benefits.**

Bilder and Mechanic (2003) studied mental disorders and physical health and their relationship to work and to application for and receipt of disability income benefits. Their definition of mental disorder was even more conservative than that used by Willis and others (2000): a diagnosis of a serious mental disorder must have been reported either on a checklist of such disorders or as the cause of an activity limitation. Persons who did not have a mental disorder, so defined, but reported another chronic condition, were classified as having a physical condition. Persons with mental disorders were much less likely than those with physical disorders (only) to be working full time—34% and 55%, respectively. People with mental disorders were also much more likely to have applied for disability income benefits (SSI or SSDI)—37% and 12%, respectively.

**Persons with disabilities caused by both mental and other medical conditions are much more likely to be unemployed and receive disability benefits than persons with only one type of disability.**

Druss and others (2000) directly addressed the effect of having both mental and physical conditions on employment and disability benefits. Based on reports of conditions causing a limitation in activity, they classified people as having limitations caused by mental conditions, by other conditions (“general medical”), by both mental and physical conditions, or as having no limitations of activity. Persons with both mental and physical conditions were more likely than any of the other groups to be unable to work (61%) and to be receiving disability income benefits (44%). Those who had mental conditions *only* were no more likely than those with general medical conditions *only* to be unable to work or receive disability income benefits. This suggests that it is the co-morbidity of mental and physical conditions, rather than mental conditions alone, which explains the relatively high levels of adverse employment outcomes for persons with mental disorders.

**The population with depression has larger proportions of younger adults, women, and single and low-income individuals, compared to the population without depression.**

**One-half of working-age adults with major depression are employed, and the probability of their working is much greater if they are in good physical health.**

The most common of the mental or emotional problems is depression. Two studies used the NHIS-D to study the prevalence and correlates of depression, Shirey (2000a) and Elinson and others (2004). Shirey, using both the NHIS-D and other data, found that compared to other adults, adults who are depressed tend to be younger, female, never married, and low income. The study shows a strong relationship between general health, as assessed by the respondent, and depression: among adults who were not depressed, 50% were reported to be in good, very good, or excellent health; but among those who were depressed, only 25% were reported to have good to excellent health.

Another study of depression, by Elinson and others (2004) focused on employment, comparing workers and nonworkers with major depression. Adults working with depression were demographically different from those not working; for instance, they were younger and better educated. The largest differences between workers and non-workers, however, were in health and functional status: the odds of working were much greater among depressed adults who were in good health and had few functional limitations.

**People with mental disorders have difficulty acquiring and maintaining health insurance coverage.**

Druss (1998) analyzed access to health care among adults with mental disorders, defined as psychiatric or substance abuse disorder, significant anxiety or depressive symptoms, or use of psychiatric medications. In a multivariate analysis, which included respondent-assessed health status and other possible confounding variables, Druss found that adults with mental disorders and those without were equally likely to have health insurance and a regular health care provider; however,



adults with mental disorders were significantly more likely to report that they had been denied insurance coverage in the past and to have stayed in a job to avoid losing health care coverage.

**Among adults who report that other people consider them to have a disability, the 11% who personally reject that label tend to have better mental health and social adjustment.**

Persons with a disability may accept it as a part of their self-identity, or they may deny it. The literature on counseling often (not always) suggests that denial is a barrier to psychosocial health that must be overcome through acceptance of an identity as a person with a disability. Olney and others (2004) tested this hypothesis directly using two NHIS-D questions on disability identity: Do others consider you disabled? Do you consider yourself disabled? Persons who answered “yes” to the first question and “no” to the second were classified as “rejecters”; those who answered “yes” to both were classified as “accepters.” A series of questions on mental health symptoms (depression, concentration, getting along, etc.) were used to measure poor psychosocial adjustment. For all measures of adjustment considered, accepters were more likely than rejecters to have symptoms of poor adjustment. The authors suggest that accepters may be accepting negative attitudes of disability common in the general culture, thereby undermining psychosocial health.

**Unlike many diseases, Alzheimer's disease is not associated with income level--low and high income persons are equally likely to be affected.**

In a general study of Alzheimer's disease, Shirey (2000b) used data from several sources, including the NHIS-D, to describe statistically the prevalence and correlates of Alzheimer's in the elderly population. The NHIS-D data presented show that Alzheimer's is associated with somewhat lower educational attainment, but unlike many other conditions, is not related to income.

#### MR/DD

The group of researchers at the Research and Training Center on Community Living at the University of Minnesota have been supported by the Department of Education's National Institute for Disability and Rehabilitation Research to analyze and disseminate data from the NHIS-D. Their research has focused on persons with intellectual disabilities (ID) or mental retardation, but many of their reports have included persons with other disabilities as a comparison group. Their work has ranged widely across different topic areas, their goal being an encyclopedic statistical description of the population of persons with ID or MR. Because their work has been broad both respect to populations and topics, individual reports in their *oeuvre* could have been discussed at several points in this research overview, and some have been discussed in other sections. However, because their work always has a focus on MR, whatever other foci it may have, most of their work is brought together in this section for comment.

A note on nomenclature: This section is headed “MR/DD” for mental retardation and developmental disability because that is the traditional and still widespread nomenclature for the disabilities it focuses on; however, many in the disability

community, including the Minnesota researchers, now use “intellectual disability” instead of “mental retardation.” In this commentary, the terms will be used interchangeably, adopting the usage of the authors whose work is being discussed.

**Although many people have both intellectual and developmental disabilities, many others have one but not the other, and the two populations differ in important ways.**

**Persons with intellectual or developmental disabilities are more likely than other persons with disabilities to be perceived as having a disability by themselves, their families, or others.**

In common usage, the terms “intellectual disability” and “developmental disability” are sometimes used interchangeably, as though they refer to the same empirical reality. The key conceptual difference between them is that the former refers to intellectual functioning only, whereas the latter refers to either (or both) mental and physical impairments. The fuller definitions of the two terms differ in other ways as well, and are important because eligibility for some tax-supported programs depends on meeting the official definition of developmental disability. Larson, Lakin, and Anderson (2003) discussed here, and Larson, Lakin, Anderson, Kwak, & Anderson (2000) discussed in the section on new definitions of disability, present the details of both definitions and describe how they operationalized each using the NHIS-D. They show that only 28% of persons who meet *either* definition also meet *both* definitions; 24% meet the definition for ID but not DD, and 48% meet the definition for DD but not ID. The authors go on to show that the two populations differ in important ways, and they note that because of its large sample size and wide range of measures, the NHIS-D presents unique opportunities for studying the two populations.

Larson, Lakin, Kwak, and Anderson (2001) continues to explore the characteristics of the ID and MR populations, this time comparing them to persons with no ID or MR but substantial functional limitations in self-care, expressive or receptive language, learning, mobility, self-direction, capacity for independent living, or economic self-sufficiency. They find that 8.1% of the population has substantial functional limitations but no ID or MR, compared to only 0.8% who have ID or MR. There are also significant differences in demography of the ID/MR and functionally limited populations; for instance, the functionally limited population is much older, on average, than the ID/MR population. There were also interesting differences in perceptions of disability among the several groups: when asked if other people would consider the sample person to have a disability, the percent of respondents saying “yes” was lowest for those who were functionally limited (50%), higher for those with intellectual disability (61%), and highest for those with developmental disabilities (83%).

**About one-fifth of persons with MR/DD have lived in a long term care facility at some time during their lives, the most common being facilities for the mentally ill, facilities for persons with MR, and nursing homes.**

**The prevalence of intellectual and developmental disabilities is higher on nonwhites than whites, but the difference is entirely explained by socioeconomic factors, not race.**

The report by Larson, Lakin, Anderson, and Kwak (2001a) is another survey of the characteristics of persons with MR or DD, but in this paper the two groups are combined and they are compared with all other persons, regardless of disability status. This approach obscures some internal differences within the two comparison groups, but it allows the authors to investigate some categories that are relatively rare or infrequent. For instance, while 84.7% of persons with MR/DD of all ages living with a relative and only 6.7% live with a spouse, among people without MR/DD, only 41% (mostly children) live with relatives, while 47% live with a spouse.

**Persons with disabilities have lower levels of health care and health status than those without disabilities, even after statistical controls for confounding factors.**

Anderson, Larson, Lakin, and Kwak (2003) presents a comprehensive assessment of health insurance, health status, use of health care services, and satisfaction with health care for persons classified as having no limitations, functional limitations only, ID, DD, or both ID and MR. Although it covers the whole population, the central interest of the authors is in ID/DD. Because of its scope, the work cannot be adequately summarized, except to say that in many respects, but not all, people with disabilities have a health disadvantage relative to persons without disabilities, and persons with ID or DD tend to fare worse than those with functional limitations only. The findings for respondent assessed health are illustrative: for persons with disabilities of any kind, the odds of being in good, fair, or poor health rather than very good or excellent health, are 4-5 times greater than the odds for people in any of the disability categories.

**Compared to adults with other disabilities, adults with intellectual or developmental disabilities are 2-3 times more likely to need help with personal care or home management activities.**

The report by Doljanac, Larson, and Lakin (2004) examines in greater detail some differences in functional limitations touched on lightly in previous reports from the research group at the University of Minnesota, primarily by exploring greater detail by age, gender, and functional limitation. One finding will illustrate the many analyses presented: in a multivariate analysis controlling for several potential confounding variables, limitations in instrumental activities of daily living were significantly greater among persons with ID or DD, women, and older persons, compared to persons with other limitations, men, and younger persons, respectively. Because of the variability they find within the population of persons with disabilities, the authors caution policy analysts from adopting policies that assume uniformity and stability over time in the needs of persons of disability.

**About three-fifths of persons with intellectual or developmental disabilities need help with home management activities, but about one-third of them have been unsuccessful in attempts to hire such help.**

The work reported in Larson, Lakin, and Huang (2003) is well summarized by the authors own words. “The primary question to be answered in this brief is to what extent do access to and experiences with various services for adults in community settings vary depending on disability group (FL only versus ID/DD), age (18 to 35 versus 36 and older), and gender. As the many analyses show, the answer is quite a bit. Of the 56 different outcomes examined, differences were noted for disability group in 47 outcomes, for age in 42 outcomes, and for gender in 26 outcomes. Differences were also frequently associated with overall health status (30 outcomes), race (22 outcomes), and economic status (33 outcomes). Clearly, awareness of the patterns of these findings is important when considering public policy decisions regarding how to best meet the needs of adults with disabilities in the non-institutional U.S. population.”

**Large proportions of women over 30 with intellectual or developmental disabilities live with relatives, usually their parents, and the proportion is over 2/3 for women with both conditions.**

As the health and care of persons with intellectual or developmental disabilities improves, they are living to more advanced ages. This is especially true of women in this population, who like women in non-disabled populations tend to live longer than men. Because of these trends, Anderson (2003) focuses on the aging process for women with MR or DD. She finds that more than one-third of women with MR or DD are over the age of 50 years, and among those with MR *only* more than one-half are over age 50. Many persons with MR or DD live with family members, usually their parents. That living arrangement, along with the “graying” of the MR/DD population, means that growing numbers of aging parents are responsible for their aging daughters: more than one-half of women with MR *or* DD are living with relatives, and among those with MR *and* DD more than two-thirds live with relatives.

**Adults with mild intellectual disability, who are usually not eligible for support services, need those services as much as those labeled "mentally retarded."**

The definition of ID (MR) was developed and applied by the Minnesota group of researchers, adhere closely to definitions developed and applied for program and policy purposes, which make their statistical estimates immediately applicable to those programs and policies. Fujiura (2003) approaches the definition issue in a different way, asking, in effect, if there are persons who do not meet the strict, programmatic definition of disability, but may have similar needs now or may in time develop such needs. Therefore, he defines a group of persons who do not have ID, *per se*, but have “mild intellectual disabilities” or “borderline mental retardation.” They include persons reported to have a learning disability that has *serious impact* on their lives or creates a *need for supports*. Fujiura finds that in every support domain (e.g., social skills, home living, work, etc.), persons with mild intellectual disability were as likely or nearly as likely to have unmet needs. If program eligibility criteria were change to include persons with mild intellectual disability, there would be substantial implications for program costs.

## G. NOT-IN-SCOPE

Some publications were identified that were about the NHIS-D but were not included in the summaries just concluded above either because they were not original analyses of NHIS data, or the NHIS-D was not the primary source of data used. Those publications are briefly described here.

Altman, Barnarrt, Hendershot, and Larson (2003) is an edited collection of articles about the NHIS-D, some of which are original analyses based entirely or large on the NHIS-D and included described elsewhere in this report, and others of which are not data analyses, but other types of articles about the NHIS-D. One of the latter is the introduction to the volume by Altman and Barnarrt (2003); another is a general overview of the history and operations of the NHIS-D by Hendershot, Larson, and Lakin (2003); and yet another is John Drabek's (2003) commentary on policy applications of the NHIS-D.

Campbell, Crews, Moriarty, and others (1999) published a surveillance report on sensory impairments (vision and hearing) that used some NHIS-D, but was based largely on other data sources. Also in 1999, Jans and Stoddard authored a chart book on women and disability, drawing on data from many sources, including some from the NHIS-D.

Iezzoni (2003b) published a monograph on limitations of walking causes by chronic condition that uses a variety of sources, including her own experience with late onset multiple sclerosis, intensive interviews with more than 100 persons with mobility limitations caused by chronic conditions, and data from the NHIS-D, some of which has been reported in other publications that are included in this summary.

In 1993, Simspon, Keer, and Cynamon reported on plans for the "1993-1994 NHIS-D" (*sic*), which was then in an early stage of development. Simpson (1994) published a description of the methods that were being employed to collect data on developmental disabilities among very young children. Neither of these reports includes any data, which had not yet been collected.

In a 2003 publication, Schacht reviewed the needs for national data on American Indians and Alaska Natives and the national survey data systems that might conceivably meet those needs. He found the design and operation of national data systems, including the NHIS-D, to have various short-comings that undermined their utility as sources of data on American Indians and Alaska Natives. Although it is a useful methodological critique, it does not contain original data analyses and does not focus primarily on the NHIS-D.

## Appendix 1: List of publications

1. [No authors listed] Use of cervical and breast cancer screening among women with and without functional limitations--United States, 1994-1995. *Morbidity and Mortality Weekly Report*. 1998 Oct 16; 47(40):853-6.
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6. Altman B, Barnarrt S, Hendershot G, and Larson S (eds.), *Using survey data to study disability: results from the National Health Interview Survey on Disability*. *Research in Social Science and Disability*, Vol. 3. 2003. Kidlington, Oxford: Elsevier.
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16. Bilder S, Mechanic D. Navigating the disability process: persons with mental disorders applying for and receiving disability benefits. The Milbank Quarterly. 2003; 81(1):75-106, table of contents.
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18. Colpe L. Estimates of mental and emotional problems, functional impairments, and associated disability outcomes for the U. S. child population in households. Pp269-278 in Manderscheid RW and Henderson MJ (eds), Mental Health U. S. 2000. 2001. Bethesda MD: Center for Mental Health Services.
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