DD Data Brief
July 2004
Vol. 6 • No. 2

Research and Training Center on Community Living • Institute on Community Integration (UCEDD)

Response Patterns Among Adult Respondents with Mental Retardation in the National Health Interview Survey, 1997-2002

Introduction

Interview surveys that collect health information on nationally representative samples of the household population use methods that assume respondents are not significantly limited in the activities of seeing, hearing, speaking, and understanding. When eligible sample persons are significantly limited in those activities, standard field procedures result in termination of the interview or substitution of a proxy respondent.

> **What is needed is a program of research and development on survey methods for respondents with mental retardation, leading to greater flexibility and better data in surveys such as the NHIS.**

The National Health Interview Survey (NHIS) is conducted annually by the National Center for Health Statistics, one of the Centers for Disease Control. Data are collected in face-to-face interviews conducted by field representatives of the Bureau of the Census. The sample represents the civilian household population of the United States, and each year interviews are completed in about 40,000 households and data are collected on about 100,000 persons.

About This *Data Brief*

This *DD Data Brief* represents a departure from previous issues, which have focused on the characteristics and needs of persons with intellectual or developmental disabilities (ID/DD) in the non-institutionalized U.S. population based on results from the National Health Interview Survey on Disability (NHIS-D) fielded in 1994-1995. In this issue, we present findings from the later years of the NHIS. We focus on one of the issues in identifying and describing the characteristics of people with ID/DD in the 1997 NHIS and later, and describe response rate and proxy response issues that disproportionately affect individuals with ID/DD.

This issue is authored by Gerry Hendershot who worked at the National Center on Health Statistics during the time the NHIS-D was fielded and is now a private consultant.

The College of Education
& Human Development
UNIVERSITY OF MINNESOTA

Since 1997, when the NHIS was redesigned, the NHIS questionnaire has had three modules: family, sample child, and sample adult. The respondent rules differ for each module. For the family module, which collects health information on all family members, the respondent can be any adult member of the family at home at the time of interview. For the sample child module, which collects additional information on one randomly-selected child in the family, the respondent must be an adult member of the family who knows about the child's health. For the sample adult questionnaire, which collects additional information on one randomly-selected adult in the family, two respondent rules have been used. From 1997 through 1999, the respondent was the sample adult – no other member of the family could respond for the sample adult. Since the year 2000, however, under specified conditions the respondent can be another adult member of the family who knows about the sample person's health. This substitution of a proxy respondent is allowed only when "absolutely necessary" if "the subject cannot participate because of a mental or physical incapacity."

The purpose of this *DD Data Brief* is to focus on the responses to the adult sample questions, examining the effects of the field procedures on patterns of response by sample persons with intellectual disabilities, with comparisons to persons limited in seeing or hearing, persons with any activity limitation, and persons with no activity limitation.

Methodology

This study examines data from the NHIS surveys conducted between 1997 and 2002 to describe response rates for various groups of adults. Figure 1 shows the items that were used to define the groups studied. During the family module interview, questions are asked about participation in major life activities. All of the questions about participation are shown in Figure 1, but because the data analyzed for this report are for adults, only questions numbers 3-8 are applicable. If any participation restrictions are reported, questions are asked about the activity limitations or impairments that cause them. Adults who reported that the cause of their activity limitation was mental retardation were identified as having mental retardation. The adults selected for the sample were classified in five categories: no limitations, limitations of any type, vision limitations, hearing limitations, and limitations due to mental retardation.

The disability categories used for this analysis are different than those used by the Research and Training Center on Community Living in previous publications based on the

Figure 1: Questions on Activity Limitation in the National Health Interview Survey Family Core Questionnaire

1. {Are/Is} {person <5 years old} limited in the kind or amount of play activities {he/she/they} can do because of a physical, mental, or emotional problem? (Not used in this study.)
2. Do any of the children under 18 in this family receive Special Educational or Early Intervention Services? (Not used in this study.)
3. Because of a physical, mental, or emotional problem, {do/does} {person} need the help of other persons with PERSONAL CARE NEEDS, such as eating, bathing, dressing, or getting around inside this home?
4. Because of a physical, mental, or emotional problem, {do/does} {person} need the help of other persons in handling ROUTINE NEEDS, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?
5. Are {you/any of these family members} limited in the kind OR amount of work {you/they} can do because of a physical, mental or emotional problem?
6. Because of a health problem, {do/does} {person} have difficulty walking without using any special equipment?
7. {Are/Is} {person} LIMITED IN ANY WAY because of difficulty remembering or because {you/they} experience periods of confusion?
8. {Are/Is} {person} LIMITED IN ANY WAY in any activities because of physical, mental or emotional problems?

1994-1995 NHIS Disability Supplement (Larson, Lakin, Anderson, Kwak, Lee & Anderson, 2001). The items used here identify far fewer adults as having mental retardation than were identified in the earlier work. Additional research is underway using the 1997 and later NHIS to try to find a more robust set of items to identify various groups. Despite this limitation, there is little question that the people identified in this brief actually have mental retardation. It is simply the case that there are probably others with mental retardation that could not be identified using these items.

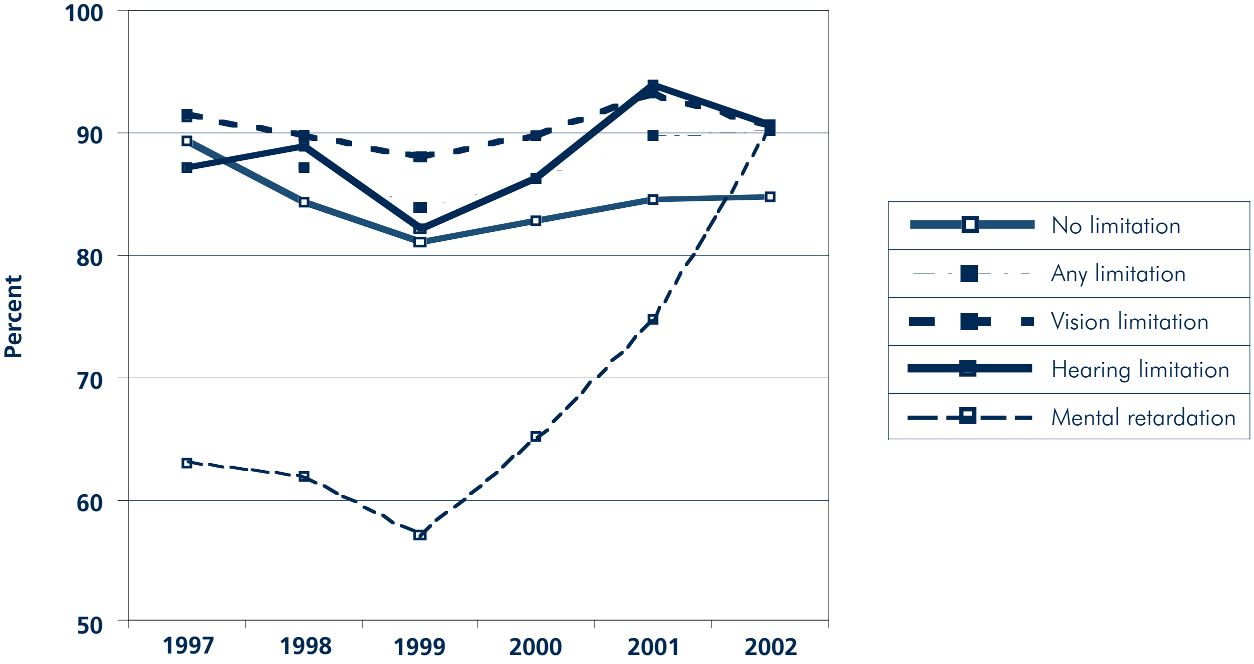
All analyses were conducted using the STATA™ statistical software package to account for both the weighting of data and the complex sampling design used in the NHIS. Where population estimates are provided, the standard error of estimate was calculated using STATA™. Standard errors are presented as relative standard error (RSE). The RSE was computed by dividing the standard error of estimate by the population estimate and multiplying the result by 100.

Results

Table 1 and Figure 2 show the NHIS case response rates for adult sample persons in data years 1997 through 2002. The case response rate is the number of completed adult sample interviews divided by the number of eligible adult sample persons, expressed as a percent. Sample adults are selected at random after the members of the household have been listed by the interviewer at the beginning of the family module interview. Case response rates are shown for all sample adults and for subgroups classified by disability.

Table 1 and Figure 2 show that the response rate for persons with no limitation of activity was 88.8% in 1997, the first year the redesigned NHIS was fielded. It declined to 83.5% in 1998, and declined again to 80.7% in 1999. When the declining response rate was detected, the National Center for Health Statistics and the Bureau of the Census instituted changes in training, evaluating, and rewarding interviewers, changes intended to improve the response rate. Those changes probably account in part for the increase in the response rate for per-

Figure 2: Response Rates by Data Year



sons with no limitation to 82.3% in 2000, 83.6% in 2001, and 83.9% in 2002.

The trend in the case response rate for adults with any activity limitation parallels that for adults without disabilities, but is slightly *higher* in every year shown. The response rates for persons limited due to vision problems or hearing problems are also higher (with one exception) than the response rates for persons without limitations. This suggests that for persons limited by vision or hearing problems, if there are barriers to survey participation they are offset by other factors, such as a greater tendency to be at home when interviewers visit or a greater tendency to cooperate when asked for an interview.

The most noteworthy feature of Table 1 and Figure 2, however, is the level of response rates for persons who are limited by mental retardation. For them the response rates are much lower in the years 1997-2001 than they are for persons without limitations, and much lower than they are for persons with other kinds of limitation. Also, while the trend in response rates over the five years parallels the trends for persons without disabilities, the "recovery" between 1999 and 2002 is much more rapid for persons with mental retardation. In fact, by 2002, the response rate for persons with mental retardation is equal to that of persons with other kinds of disability. It seems unlikely that the changes in procedures made in response to the decline in response rates would have had such a differential effect on persons with mental retardation. It seems more likely that another change introduced in 2000 (and already mentioned) is the cause of the sudden

Table 1: Percent of Sample Adults Who Completed the Adult Sample Questionnaire, According to Data Year and Activity Limitation Status: National Health Interview Survey, 1997-2002

Activity Limitation Status	1997	1998	1999	2000	2001	2002	1997-2002
	Percent (standard error)						
All statuses	89.3 (0.2)	84.2 (0.3)	81.0 (0.3)	82.8 (0.3)	84.5 (0.3)	84.7 (0.3)	84.4 (0.2)
No limitation	88.8 (0.2)	83.5 (0.3)	80.7 (0.3)	82.3 (0.3)	83.6 (0.3)	83.9 (0.3)	83.8 (0.2)
Any limitation	91.5 (0.4)	87.2 (0.5)	83.9 (0.6)	86.2 (0.5)	89.7 (0.4)	90.1 (0.4)	88.1 (0.2)
Vision limitation	91.3 (1.1)	89.7 (1.2)	87.9 (1.4)	89.8 (1.5)	93.1 (1.0)	90.5 (1.6)	90.4 (0.5)
Hearing limitation	87.1 (2.0)	88.8 (2.1)	82.1 (2.3)	86.2 (2.3)	93.8 (1.3)	90.5 (1.9)	88.2 (0.8)
Mental retardation	63.0 (5.4)	61.8 (5.2)	57.1 (5.8)	65.0 (8.1)	74.7 (4.9)	90.4 (3.4)	68.3 (2.3)
	Sample Cases						
All statuses	103,477	98,785	97,059	100,618	100,760	93,386	594,085
No limitation	89,887	86,417	84,366	88,177	88,295	81,489	518,631
Any limitation	13,590	12,368	11,772	11,652	12,091	11,521	72,994
Vision limitation	1,009	868	834	816	904	801	5,232
Hearing limitation	541	468	440	424	475	485	2,833
Mental retardation	202	180	184	198	196	176	1,136

Table 2: Percent of Respondents Who Were Proxies, Sample Adult Questionnaire, National Health Interview Survey, 2001-2002

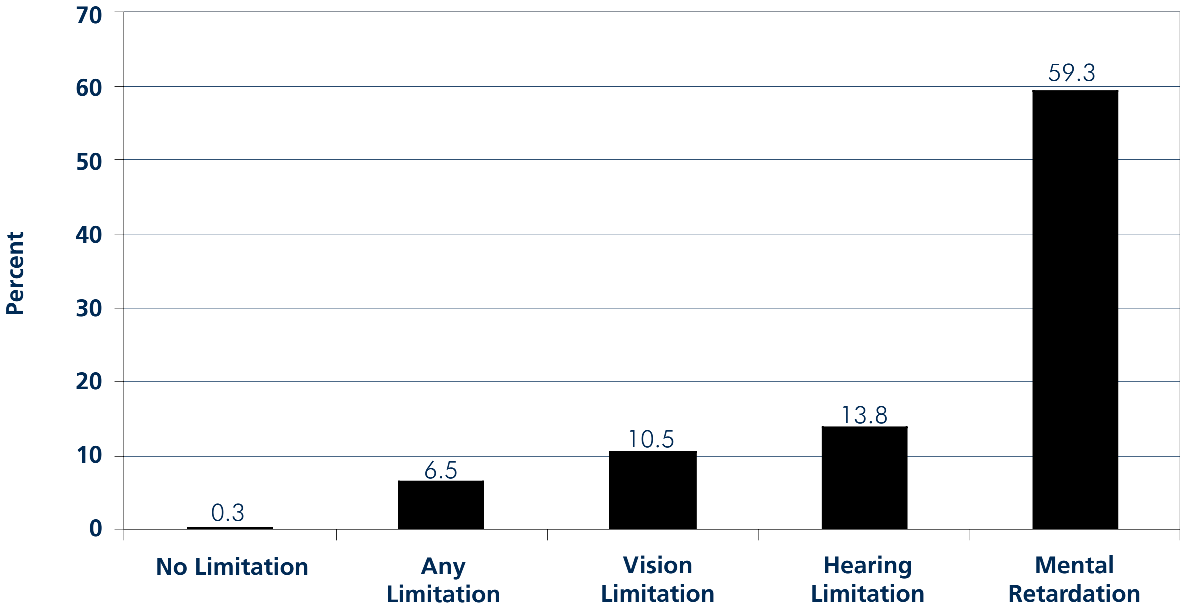
Activity Limitation Status	% Proxy	(Standard Error)	RSE %
All statuses	1.2	(0.1)	6.7
No limitation	0.3	(0.0)	14.7
Any limitation	6.5	(0.5)	7.1
Vision limitation	10.5	(1.8)	16.6
Hearing limitation	13.8	(2.6)	18.6
Mental retardation	59.3	(6.7)	11.3

improvement – the easing of the prohibition of using proxy respondents.

That hypothesis can be addressed indirectly by the data in Table 2 and Figure 3, which show the percent of completed cases in which a proxy respondent, not the sample person, was interviewed. While the change in the proxy rule was introduced in 2000, it was not until 2001 that interviewers recorded whether the respondent was the sample person or a proxy, so 2001 and 2002 are the only years for which the information is available at the time of this writing.

Table 2 and Figure 3 show that among persons with no activity limitations the use of proxy respondents is very rare, less than 1%. The rate for persons with any limitation of activity is relatively much higher, 6.5%. This suggests that when interviewers substitute a proxy respondent it is almost always because the sample person has an activity limitation. The proxy rate is higher for sample persons limited by vision and hearing problems; however, the largest difference is for sample persons with mental retardation, among whom a *majority* of interviews were completed by proxy respondents. It is clear that the higher response rates for sample persons with mental retardation in 2001-2002 were made possible by the rule change in 2000 that allowed interviewers greater freedom to use proxy respondents. This suggests that the very low rates of response *before* 2000 resulted from interviewers concluding that respondents with mental retardation were not capable of responding for themselves.

Figure 3: Percent Proxy Response by Disability



Subjective and Sensitive Questions and Item Nonresponse

The high rate of proxy response for sample persons with mental retardation is not necessarily undesirable from the viewpoint of data quality. By using a proxy, interviews can be completed which would otherwise not have occurred at all. Even when a person with mental retardation could have been interviewed, a proxy may provide information of equal or better quality. In one study, for instance (Perry and Felce, 2002), the interview responses of sample persons with mental retardation were compared with the responses of proxy respondents for sample persons with mental retardation. It was found that there was good correspondence in the responses of self- and proxy respondents for *objective* measures; however, correspondence was not good for *subjective* measures. Presumably proxy respondents can have independent knowledge of objective circumstances of the sample person's life, but proxies have less access to the interior cognitions and affective states of the sample person.

There is no way to evaluate directly the accuracy of information given by proxy respondents in response to subjective questions in the NHIS. There is an indirect indicator, however: item nonresponse or missing data. If a proxy respondent is asked to provide information on a subjective state of the sample person, and does not know what that state is, the proxy may say they do not know the answer or simply not give an answer. In an interview where there are a number of such subjective questions and a proxy respondent has indicated an inability to answer such questions, it is also possible that the interviewer may begin to skip over subjective questions. In any case, the question is not answered, and the datum becomes an item nonresponse.

Table 3: Percent of Cases That Were Missing Data on Selected Subjective and Sensitive Questions, Sample Adult Questionnaire, National Health Interview Survey, 2001

Activity Limitation Status	Missing Data on Any of Three Subjective Questions			Missing Data on Any of Three Sensitive Questions		
	% Missing	(Standard Error)	RSE %	% Missing	(Standard Error)	RSE %
All statuses	2.5	(0.1)	4.8	6.6	(0.2)	3.0
No limitation	2.1	(0.1)	5.3	6.0	(0.2)	3.3
Any limitation	5.1	(0.4)	7.5	9.9	(0.5)	5.1
Vision limitation	5.7	(1.1)	19.5	11.3	(1.7)	14.9
Hearing limitation	8.1	(2.0)	24.4	9.7	(2.1)	21.6
Mental retardation	25.5	(6.5)	25.5	21.6	(5.6)	26.1

Subjective Questions

1. How often do you get the social and emotional support you need?
2. In general, how satisfied are you with your life?
3. During the past 30 days, how often did you feel happy?

Sensitive Questions

4. Have you ever been tested for HIV?
5. What are your chances of GETTING HIV (the virus that causes AIDS)?
6. Tell me if any of these statements is true for you: You have hemophilia and have received clotting factor concentrations; You are a man who has had sex with other men (even just one time); You have taken street drugs; You have traded sex for money or drugs (even just one time); You have tested positive for HIV, the virus that causes AIDS; You have had sex (even just one time) with someone who would answer "Yes" to any of these statements.

Table 3 and Figure 4 show a measure of item nonresponse for the three *subjective* questions:

- How often do you get the social and emotional support you need?
- In general, how satisfied are you with your life?
- During the past 30 days, how often did you feel happy?

For this analysis, if any of the three questions was not answered, the case was regarded as having missing data. The percent of cases with missing data on the three subjective items is shown for persons classified by activity limitation. The level of missing data for persons with no activity limitation is 2.1%, which is about the level of missing data for most NHIS questions, objective or subjective. The level of missing data is greater for persons with activity limitations and *much* greater for persons with mental retardation: for more than one-fourth of the sample persons with mental retardation, answers to one or more of the three subjective questions were not recorded. Most survey analysts would regard this is as an unacceptably high level of item nonresponse.

To demonstrate that the high level of missing data for persons with mental retardation was due to proxy respondents, it would be necessary to repeat the analysis shown in Figure 4 for sample persons with mental retardation, separating proxy from self-respondents. That analysis was done but is not presented here because the sampling errors of the point estimates are very large. However, that analysis can be done for persons with any limitation of activity, who have a moderately elevated level of missing data compared to persons without a limitation. The results are shown in Table 4 and Figure 5, which clearly demonstrate that missing data are much more common when the respondent is a proxy rather than a self-respondent, regardless of the limitation status of the sample person. When sample persons with limitations of activity respond for themselves, item nonresponse is very low and not significantly different from the rate for persons without limitations. This is evidence that the overall higher level of missing data for persons with limitations is almost entirely due to their having proxy respondents more often.

Figure 4: Percent Missing Data on Subjective Questions by Disability Group

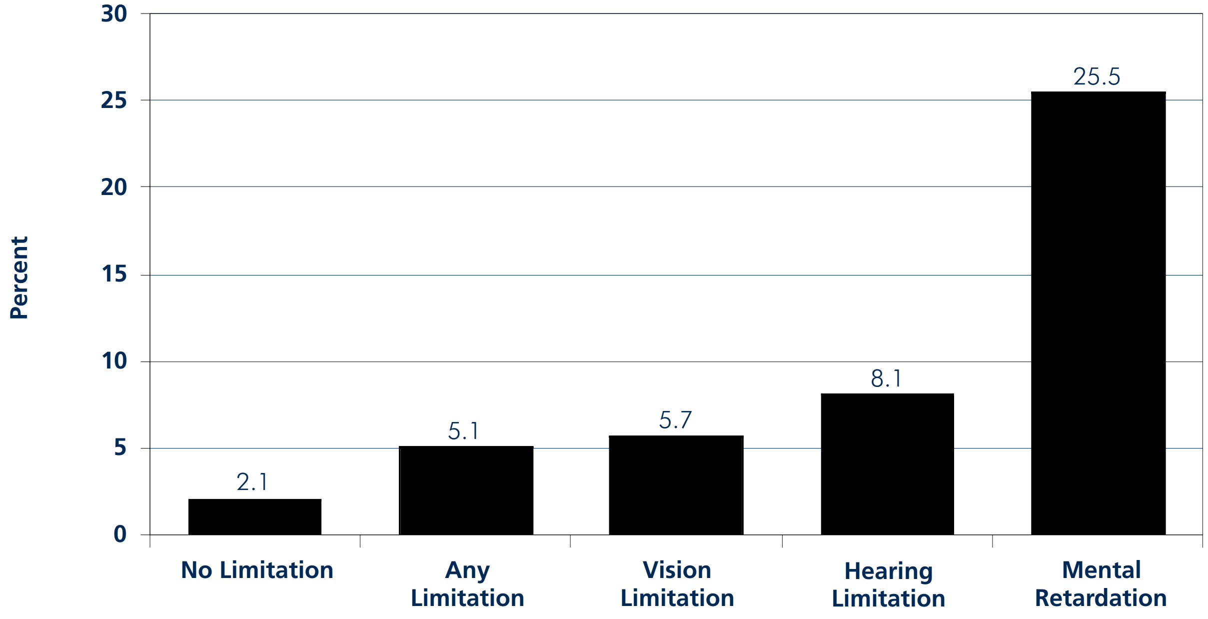


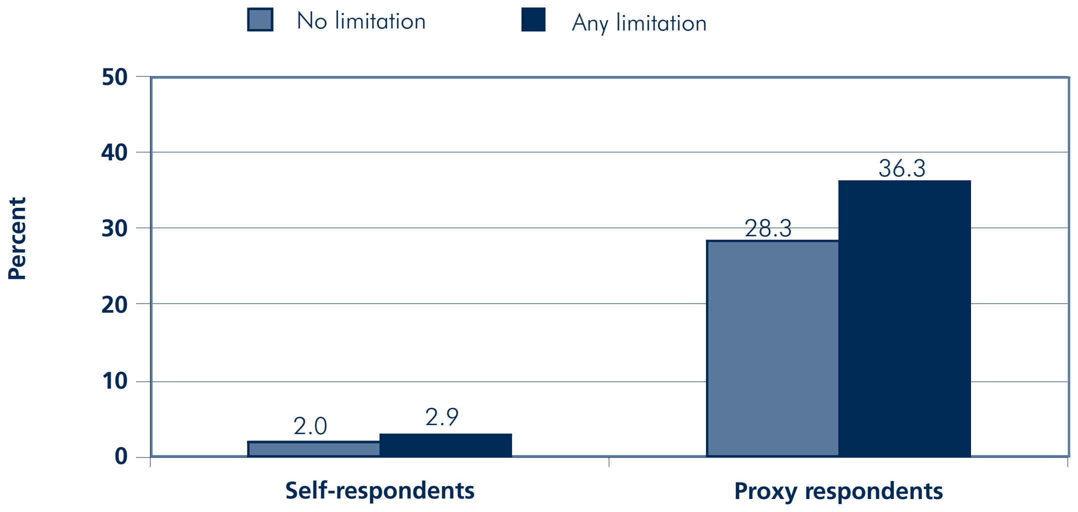
Table 4: Percent of Cases That Were Missing Data on Selected Subjective and Sensitive Questions, Sample Adult Questionnaire, National Health Interview Survey, 2001

Activity Limitation Status	Missing Data on Any of Three Subjective Questions			Missing Data on Any of Three Sensitive Questions		
	% Missing	(Standard Error)	RSE %	% Missing	(Standard Error)	RSE %
Self-respondents						
All statuses	2.1	(0.1)	5.1	6.2	(0.2)	3.2
No limitation	2.0	(0.1)	5.5	5.9	(0.2)	3.4
Any limitation	2.9	(0.3)	9.2	8.2	(0.4)	5.4
Proxy respondents						
All statuses	34.7	(3.0)	8.8	34.5	(3.2)	9.3
No limitation	28.3	(6.5)	23.0	34.7	(7.7)	22.3
Any limitation	36.3	(3.3)	9.1	34.5	(3.5)	10.0

As noted above, proxy respondents may have independent information about objective circumstances which enable them to answer questions about those circumstances for sample persons with activity limitations. While that may be generally true, some information about sensitive matters may be kept very private, so that proxies do not have independent information about them. If so, a high level of item nonresponse would be expected from proxy respondents for sensitive questions. That in turn would result in high levels of missing data for sensitive questions among sample persons with limitations of activity, especially those with mental retardation, because proxy respondents so often answer for them.

To test that hypothesis, item nonresponse was measured for three *sensitive* questions:

Figure 5: Percent Missing Data on Subjective Questions by Limitation Status and Respondent Type



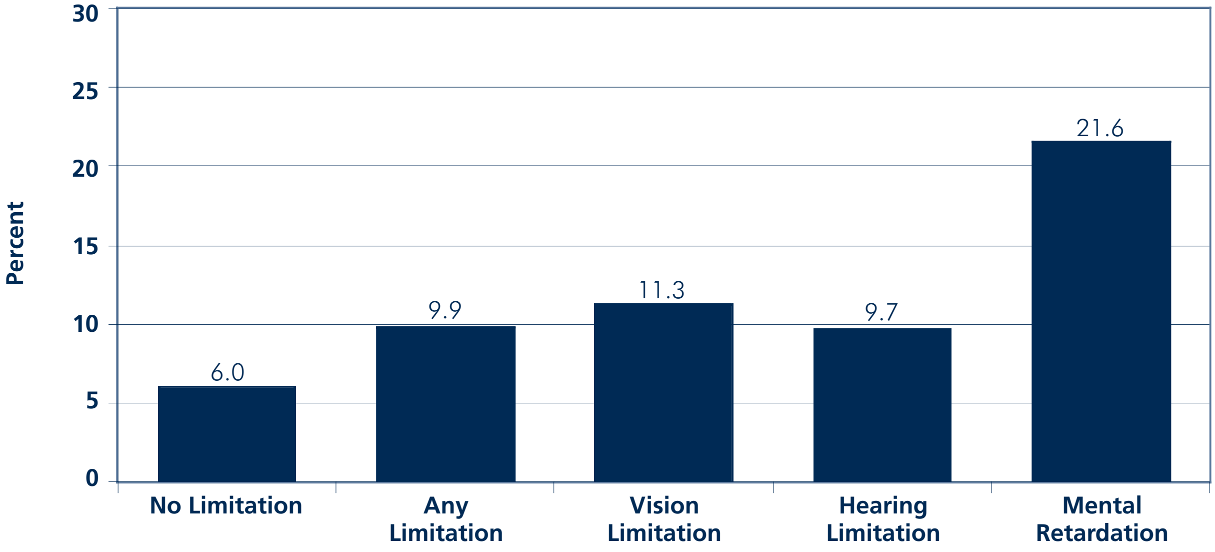
- Have you ever been tested for HIV?
- What are your chances of GETTING HIV (the virus that causes AIDS)?
- Tell me if any of these statements is true for you: You have hemophilia and have received clotting factor concentrations; You are a man who has had sex with other men (even just one time); You have taken street drugs; You have traded sex for money or drugs (even just one time); You have tested positive for HIV, the virus that causes AIDS; You have had sex (even just one time) with someone who would answer "Yes" to any of these statements.

The analysis of these questions is shown in Table 3 and Figure 6. The percent of persons with missing data on one or more of the three sensitive questions is relatively low for persons with no activity limitation, higher for persons with any activity limitation, and highest for persons with mental retardation – more than one-fifth of sample persons with mental retardation were missing data. We interpret the high level of item nonresponse for persons with mental retardation as resulting from the frequent use of proxy respondents for those persons. An analysis comparing item nonresponse for proxy and self-respondents among sample persons with mental retardation tends to support that interpretation, but the statistics do not meet the usual standards for reliability and are not presented here. However, an analysis for persons with any limitation, shown in Table 4 and Figure 7, is consistent with our interpretation: levels of missing data are much higher for proxy respondents, regardless of the limitation status of the sample person.

Discussion

From 1997 through 1999, the NHIS case response rate for sample adults with mental retardation was much lower than the rate for persons who were blind, deaf, or had no limitation of activity. In the year 2000, a change in NHIS field procedures made it easier for interviewers to substitute proxy respondents when they felt sample persons could not respond for themselves. As a result of that change, proxy respondents were much more common in 2001 and 2002, especially when the sample adult had mental retardation. This resulted in a great improvement in the overall case response rate for sample adults with mental retardation, and by 2002 the response

Figure 6: Percent Missing Data on Sensitive Questions by Disability Group



rate for persons with mental retardation was as high as the rate for persons with no limitation. While the case response rate improved dramatically, the item response did not: for people with mental retardation, about 25% had missing data for selected questions of a subjective or sensitive nature, and the high rate of missing data almost certainly is due to the substitution of proxy respondents for those sample adults.

It is difficult to obtain information for persons with mental retardation in surveys that use standardized field procedures and measurement instruments. If field procedures require self-response, as did the NHIS from 1997 through 1999, then interviews will not be completed for many respondents with mental retardation. On the other hand, if proxy respondents are allowed, as they were in the NHIS from 2000 on, the interviews are more likely to be completed, but at the cost of unacceptable levels of item nonresponse for some questions.

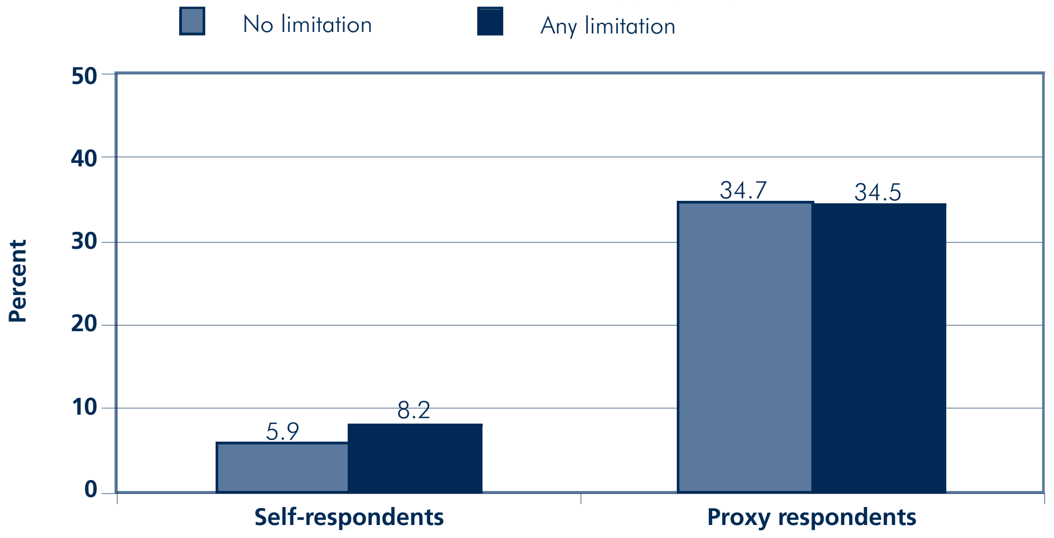
In some smaller scale studies of persons with mental retardation, techniques have been developed for obtaining information by self-response from persons with mental retardation. For reasons of cost, it probably is not feasible to fully apply those techniques in large surveys such as the NHIS. However, it may be possible to adapt some of those techniques for the large survey setting. What is needed is a program of research and development on survey methods for respondents with mental retardation, leading to greater flexibility and better data in surveys such as the NHIS.

References

Larson, S.A., Lakin, K.C., Anderson, L, Kwak, N., Lee, J.H., Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal on Mental Retardation*, *106*, 231-252.

Perry, J. & Felce, D. (2002). Subjective and objective quality of life assessment: Responsiveness, response bias, and resident/Proxy Concordance. *Mental Retardation*, *40*(6), 445-456.

Figure 7: Percent Missing Data on Sensitive Questions by Limitation Status and Respondent Type



Online RTC Resources

The following Research and Training Center on Community Living (RTC) research and policy publications are available online and may be of interest to readers of this *DD Data Brief*:

DD Data Brief (http://rtc.umn.edu/nhis/pubs.html)

A series summarizing analyses of the 1994/1995 National Health Interview Survey Disability Supplement, conducted by the Institute's Research and Training Center on Community Living. Available are the following issues:

- Gender, Age, and Disability Differences in Functional Limitations for Non-Institutionalized Adults in the NHIS-D. (2004)
- Service Use by and Needs of Adults with Functional Limitations or ID/DD in the NHIS-D: Difference by Age, Gender, and Disability. (2003)
- Health Insurance Coverage and Health Care Experiences of Persons with Disabilities in the NHIS-D. (2003)
- Children with Disabilities: Social Roles and Family Impacts. (2002)
- Functional Limitations of Adults in the U.S. Non-Institutionalized Population. (2001)
- Demographic Characteristics of Persons with MR/DD Living in Their Own Homes or with Family Members. (2001)
- Characteristics of and Service Use by Persons with MR/DD Living in Their Own Homes or with Family Members. (2001)
- Prevalence of Mental Retardation and/or Developmental Disabilities. (2000)

Policy Research Brief (http://ici.umn.edu/products/newsletters.html#policy)

A newsletter summarizing research on policy issues affecting persons with developmental disabilities. Published by the Institute's Research and Training Center on Community Living. Issues summarize research on the following topics:

- Costs and Outcomes of Community Services for Persons with Intellectual and Developmental Disabilities. (2004)
- Medicaid Home and Community-Based Services: The First 20 Years. (2003)
- Wages of Direct Support Professionals Serving Persons with Intellectual and Developmental Disabilities: A Survey of State Agencies and Private Residential Provider Trade Associations. (2003)
- Alternative Schools and Students They Serve: Perceptions of State Directors of Special Education. (2003)
- Health Status, Health Care Utilization Patterns, and Health Care Outcomes of Persons with Intellectual Disabilities: A Literature Review. (2002)
- Family Support for Families of Persons with Developmental Disabilities in the U.S.: Status and Trends. (2001)
- Do We Really Mean Families for All Children? Permanency Planning for Children with Developmental Disabilities. (2000)
- "No Right is More Precious": Voting Rights and People with Intellectual and Developmental Disabilities. (2000)
- Behavioral Outcomes of Deinstitutionalization for People with Intellectual Disabilities: A Review of Studies Conducted Between 1980 and 1999. (1999)
- A Decade Later: Employment, Residential, and Social Changes in the Lives of Adults and Young Adults with Moderate and Severe Disabilities. (1998)

DD Data Brief

July 2004, Vol. 6, No. 2

Issue Author —

Gerry E. Hendershot, Ph.D.

Issue Editors —

Sheryl A. Larson
K. Charlie Lakin

Research and Training Center on Community Living,
Institute on Community Integration, University of Minnesota

DD Data Brief is published periodically by the Research and Training Center on Community Living and Institute on Community Integration (UCEDD), College of Education and Human Development, University of Minnesota. Funding for this data analysis was provided by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education through a grant to the Research and Training Center (RTC) on Community Living at the University of Minnesota (Cooperative Agreement No. H133G980082), a NIDRR-funded Field Initiated project (Cooperative Agreement No. H133G020037), and a subcontract from the NIDRR-funded RTC on Aging and Developmental Disabilities at the University of Illinois at Chicago (Cooperative Agreement No. H133B980046). Supplemental funding for printing was provided by the Administration on Developmental Disabilities (Grant #90DH006401). All analyses, interpretations, and conclusions are those of the authors.

Inquiries about *DD Data Brief* can be directed to —

Publications Office
Institute on Community Integration
University of Minnesota
109 Pattee Hall
150 Pillsbury Drive S.E.
Minneapolis, MN 55455

phone: 612-624-4512
fax: 612-624-9344
e-mail: publications@icimail.umn.edu
Web: http://rtc.umn.edu/nhis

DD Data Brief is available in alternative formats upon request from the address above.

Institute on Community Integration
University of Minnesota
109 Pattee Hall
150 Pillsbury Dr. S.E.
Minneapolis, MN 55455

Address Service Requested

Non Profit Org.
U.S. Postage
PAID
Minneapolis, MN
Permit No. 155