

**DFS - 100**  
(1994)



**DISABILITY  
FOLLOWBACK  
SURVEY**

*Field Representative's  
Manual*

U. S. Department of Commerce  
BUREAU OF THE CENSUS

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## CHAPTER 1. DESCRIPTION OF THE SURVEY

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### DESCRIPTION OF THE DISABILITY FOLLOWBACK SURVEY

The Bureau of the Census is conducting the Disability Followback Survey (DFS) for the National Center for Health Statistics to obtain objective and descriptive information about disability, polio survivorship, and aging. Specific topics in the DFS questionnaires differ for various age groups. For example, we ask about assistive devices, mental health services, home health services, and education/recreation services for children under 18. For adults (18+), the topics include housing and long-term care, transportation, social activities, vocational rehabilitation, and use of other medical services. The DFS is actually a continuation of the 1994 National Health Interview Survey (HIS) Disability Supplement, but is being administered as a separate survey.

#### A. PURPOSE

The main purpose of the DFS is to obtain additional information on disability and its impact on the well-being of the U.S. population. Also, with the 1990 passage of the *Americans with Disabilities Act (ADA)*, a wide range of information about disabilities is required to monitor the effects of this legislation.

As the proportion of our elderly population increases, the maintenance of good health and functional independence among the elderly is one of the most important goals of the health care community. To provide current estimates on the health and functional status of the elderly, the DFS contains a separate sample of persons 70+ years of age.

#### B. AUTHORITY

The authority to conduct the DFS comes from *Title 42, United States Code, Section 242k*.

#### C. SAMPLE DESIGN

The DFS sample consists of approximately 20,000 persons of various ages and 7,000 persons 70+ years of age, selected from families interviewed during the 1994 HIS. Based on the answers to questions in the original HIS interview, more than one person from some families may be selected for the DFS, while no one from other families may be selected.

#### D. THE NATIONAL HEALTH INTERVIEW SURVEY (NHIS)

As mentioned above, the National Health Interview Survey is the source of the sample for the Disability Followback Survey. Below is a description of the topics covered in the HIS interview, so you will be familiar with the type of interview the family has already completed.

The National Health Interview Survey (NHIS) is a nationwide survey conducted by the Bureau of the Census for the National Center for Health Statistics (NCHS). The purpose of the HIS is to obtain information about the amount and distribution of illness, its effects in terms of disability and chronic impairments, and the kind of health services people receive.

The basic core HIS interview asks family members about visits to doctors, hospital stays within the past year, whether they are limited or restricted in their normal activities or ability to work because of health conditions, detailed questions on their health conditions, and basic demographic information such as education, marital status and income. The 1994 HIS-2 supplement questionnaire includes questions on immunization and disability.

The HIS core questionnaire collects information on every civilian member of the family, while some supplements, such as Immunization, Year 2000 Objectives, and AIDS Knowledge concentrate mostly on one sample person. The time to complete the core questionnaire ranges from 20 minutes to over an hour, depending on the number of family members and the health conditions reported. The various supplements range from about 30 minutes to well over an hour.

## **E. CONFIDENTIALITY**

### **1. What is Confidentiality?**

The term "confidentiality" refers to the guarantee that is made to individuals who provide survey information regarding disclosure of that information to others, as well as the uses of that information.

The specific guarantee of confidentiality can vary by survey. This part of the manual explains the guarantee of confidentiality given to respondents in the Disability Followback Survey (DFS), and what you should do to maintain this guarantee. Your 11-55, Administrative Handbook, also contains information on nondisclosure policies, violations of confidentiality, and ways to prevent careless disclosure. When you were appointed as a Field Representative, you signed an affidavit to protect the confidentiality of the survey information you collect. You also are required to sign a semiannual certification of compliance with the Census Bureau's nondisclosure policy.

### **2. The Guarantee of Confidentiality**

The U.S. Public Health Service provides the guarantee of confidentiality for the Disability Followback Survey. This guarantee is contained in the "Notice" statement printed on the cover of the questionnaires.

"Information contained on this form which would permit identification of any individual or establishment has been collected with a guarantee that it will be held in strict confidence, will be used only for purposes stated for this study, and will not be disclosed or released to others without the consent of the individual or the establishment in accordance with section 308(d) of the Public Health Service Act (42 USC 242m)."

A similar statement is also made on the advance letters to fulfill the requirements of the Privacy Act of 1974.

3. Authorized Persons

The agreement between the Bureau of the Census and the sponsor regarding the confidentiality of the data collected in the HIS briefly states that the sponsor's employees (including contractors and grantees) may not disclose the data in a form permitting identification of any individual or establishment, and may not use the data for law enforcement, regulatory, or any other purposes that are inconsistent with the stated purpose(s) of the survey. The sponsor is responsible for enforcing the conditions of the agreement and may authorize non-Census employees to observe interviewing or review completed questionnaires. These persons will have the same restrictions and penalties as you regarding the treatment of confidential data. Anyone who is not a Bureau of the Census employee or properly authorized by this Title 15 survey sponsor to view confidential data is referred to as an "UNAUTHORIZED PERSON."

4. Penalties for Disclosing Confidential Information

Unauthorized disclosure of individual information collected in the Disability Followback Survey is punishable by a fine of up to \$1,000, or imprisonment up to 1 year, or both (18 USC 1905). Deliberate falsification, by an employee, of any information in this survey is punishable by a fine up to \$10,000, or imprisonment up to 5 years, or both (18 USC 10001).

5. How to Maintain Confidentiality

- a. When No One is Home at the Sample Person's Address: You may ask a neighbor, apartment manager, or someone else living nearby when they expect someone to be home. When requesting this information, do not mention the Disability Followback Survey by name and do not attempt to describe the survey. To gain cooperation, you may say:

*"I am \_\_\_\_\_ from the United States Bureau of the Census. Here is my identification (show ID). I am conducting a survey and I would like to know when (sample person) will be at home." (or something similar)*

- b. When Trying To Locate Sample Persons: When asking for the telephone number and/or address, do not mention the DFS by name and do not attempt to describe the survey. Instead, you may say:

*"I am \_\_\_\_\_ from the United States Bureau of the Census (show ID); I'm trying to locate (sample person's name). Do you have a current [address/telephone number] for (sample person's name) which you can give to me?"*

- c. When Conducting Interviews: Do not permit unauthorized persons (including members of your family) to listen to an interview. For example:
1. When conducting a personal visit interview, if persons not participating in the survey are present (e.g., neighbors, friends, other "non-family" members), use your discretion in asking the respondent if he/she wants to be interviewed privately. Since this may be awkward to ask in some situations, you might ask if another time would be more convenient. If so, make the necessary arrangements to accommodate the respondent.
  2. When conducting an interview in which an interpreter is required, ask the respondent if he/she is willing to have another person act as interpreter. If the respondent objects to the interpreter and a more suitable one cannot be located at the time of the interview, call the office to see if someone who speaks the respondent's language can conduct the interview.
- d. When Discussing Your Job With Family, Friends, Other: You must not reveal any information which you obtained during an interview or identify any persons who participated in the survey to unauthorized persons in conversation or by allowing them to look at labeled questionnaires, whether filled or not.
- e. When "Storing" Completed Questionnaires: If it becomes necessary to have DFS questionnaires around your home, motel room, car or other nonsecure place when you will not be there, put them "out-of-sight" if they cannot be more securely stored, so that unauthorized persons will not be tempted to look at them.

6. Subpoena of Records

In the event of a record collected in the Disability Followback Survey being subpoenaed, any Census Bureau employee upon whom such subpoena is served will communicate with the Director of the Bureau of the Census through the regional office. Action to satisfy such subpoena will be taken only as authorized by Public Health Service Regulations, section 1.108 of Title 42, U.S.C.

F. THE PRIVACY ACT

The Privacy Act, passed by Congress in 1974, insures that personal information collected by Federal agencies is maintained in a manner which prevents intrusions upon individual privacy.

This act requires that when Federal agencies request information from an individual the following be provided to that individual:

- The authority under which the information is being collected and whether compliance is mandatory or voluntary.
- The principle purpose or purposes for which the information is intended to be used.



- The effects on the respondent, if any, for not providing all or any part of the requested information.

For the DFS, this information is contained in the DFS-60 advance letters. However, all sample persons or parents/guardians may not have received these letters. During your contact with the sample persons and/or the parents/guardians, you must ask whether the letter was received. If a letter was not received, give a copy of the letter if this is a personal visit, or if this is a telephone call, offer an explanation of the DFS in your own words, but similar to the following:

*"The Bureau of the Census is conducting the Disability Followback Survey for the National Center for Health Statistics, which is part of the U.S. Public Health Service. The purpose of the survey is to obtain additional health information on people who are elderly or reported in an earlier interview that they had health problems.*

*This survey is voluntary and is authorized by the Public Health Service Act (Title 42, United States Code, Section 242k). Although there are no penalties for failing to reply, each unanswered question substantially lessens the accuracy of the final data. All answers are strictly confidential and the identity of individuals will not be disclosed by either the Bureau of the Census or the Public Health Service without written approval."*

## CHAPTER 2. THE DFS FORMS AND FIELD REPRESENTATIVES ASSIGNMENTS

### **A. DESCRIPTIONS OF FORMS**

1. DFS-1, Children's Questionnaire - This questionnaire is used to collect information for selected sample children under 18 years of age. A desired respondent will be specified for each sample child.
2. DFS-2, Adult's Questionnaire - This questionnaire is used to collect information for selected sample adults 18 years of age or older. Whenever possible, the sample person him/herself should be interviewed.
3. DFS-3, Elderly's Questionnaire - This questionnaire is used to collect information for selected sample adults 70+ years of age who were not selected to receive the DFS-2. Whenever possible, the sample person him/herself should be interviewed.
4. DFS-4, Polio Survivor's Questionnaire - This questionnaire is used to collect information about the effects of polio both currently and in the past for identified survivors of polio. In most cases, this will be administered in conjunction with the DFS-2 or DFS-3.
5. DFS-10, Flashcard Booklet - This booklet contains a set of cards used for reference during the interview.
6. DFS-60, Advance Letter - This letter informs the sample adults or desired respondent for the sample children what the survey is about and that a Census field representative will be contacting them shortly. Mail it about 1 week before you intend to contact the sample adults or desired respondent for the sample child.
7. DFS-100 Field Representative Manual - This manual contains the procedures and instructions for completing the DFS.
8. DFS-101, Field Representative's Initial Self-Study - This is part of the initial training self-study which all field representatives must complete before beginning work on the DFS.
9. DFS-102, Refresher Self-Study - This is a self-study which FRs who have worked on the previous DFS wave must complete before beginning interviewing in the current wave.

### **B. ASSIGNMENTS**

1. Schedule - The 1994 DFS will be conducted in three waves. Each wave consists of 8 weeks.
2. Materials - You should have the following materials for each DFS assignment.
  - Labeled DFS questionnaires

- 1 blank DFS Child's Questionnaire
- 3 blank DFS-2 Adult's Questionnaires
- 1 blank DFS-3 Elderly Questionnaire
- 1 blank DFS-4 Polio Survivor's Questionnaire
- A DFS-60 Advance Letter for each case in the assignment
- Maps, listing sheets from the HIS segment folder (if appropriate)
- A supply of envelopes for mailing the DFS-60 Advance Letter
- A small supply of envelope and return envelopes for mailing the **Provider Request Form** at the end of the DFS-4 Polio Questionnaire
- A supply of large envelopes with the regional office address preprinted to mail your completed questionnaire to the regional office

C. **MAILING COMPLETED WORK TO THE REGIONAL OFFICE**

Mail completed DFS questionnaires to the regional office on a flow basis as they are completed. **DO NOT** hold your completed work until the end of the wave.

## **CHAPTER 3. TRAINING**

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### **A. INITIAL TRAINING**

The first wave you have a Disability Followback Survey (DFS) assignment, you must complete an initial training self-study and attend a 2-day classroom training session. You should receive the following materials with the initial self-study:

- 1 DFS-100 Field Representative's Manual
- 1 DFS-101 Field Representative's Initial Self-Study
- 1 DFS-1, Children's Questionnaire
- 1 DFS-2, Adult's Questionnaire
- 1 DFS-3, Elderly's Questionnaire
- 1 DFS-4, Polio Survivor's Questionnaire
- 1 DFS-10, Flashcard Booklet
- 1 DFS-60, Advance Letter

### **B. CLASSROOM TRAINING**

You will attend a two day classroom training session prior to the start of interviewing for the DFS. Your regional office will notify you of the date and location of your classroom training. **TAKE YOUR DFS 101 FIELD REPRESENTATIVE'S SELF-STUDY ALONG WITH YOUR DFS-100 FIELD REPRESENTATIVE'S MANUAL TO THE CLASSROOM TRAINING.**

### **C. REFRESHER TRAINING**

If you work in consecutive waves of the DFS, you must complete the DFS-102 Refresher Self-Study prior to beginning interviewing in the second (or third) wave in which you work.

If you do not work in consecutive DFS waves, that is, there is a break between the waves you actually do work, you must complete the Initial Training Self-Study again and attend the classroom training before working on the DFS for the upcoming wave.

### **D. PAYROLL**

Charge time worked on the DFS to the following project and operation codes:

- Project Code: 7247
- Operation Codes:
  - Self-Study and  
Classroom Training 60
  - Interviewing 63

## CHAPTER 4. GENERAL INTERVIEWING INSTRUCTIONS

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### A. GUIDELINES FOR ASKING QUESTIONS

Follow these guidelines when asking the various questions on the DFS questionnaire:

- **Always remain neutral** - You must maintain a neutral attitude with respondents. Nothing in your words or manner should imply criticism, surprise, approval, or disapproval of the questions asked or of the respondent's answers. This does not mean that you should appear cold or harsh. Accept his or her answers with understanding and patience.
- **Ask all questions in the order presented on the questionnaire** - Never change the order of the questions on the questionnaire. The questions follow one another in a logical sequence, in fact, some questions may be asked later so as not to affect answers to earlier questions.
- **Ask all questions exactly as worded** - Do not change even one small word in any question. Simply repeat the question if the need arises. If you do repeat the question, read all the words in the question.
- **Do not let the respondent see the questions** - Respondents can be influenced by knowing what questions are coming next or by seeing the answer categories. We provide flashcards for those questions where we want the respondent to see the answer choices.
- **Do not read answer categories to respondents unless they are part of the question** - Only read the answer categories when they are part of the question, when you are instructed to on the questionnaire or in this manual, or when the question uses a flashcard and you are conducting a telephone interview or the respondent cannot or will not read the flashcard answer categories.

When a question instructs you to "*HAND CARD*," this means that you are to show the specified flashcard from the DFS-10 to the respondent if it is a personal visit. If you are conducting a telephone interview or if the respondent cannot or will not read the flashcard, then read the answer categories to the respondent.

## B. TYPES OF QUESTIONS

You will encounter the following types of questions in the DFS questionnaire:

### 1. Precoded Questions

These questions contain the answer-choices to the question. The simplest form of a precoded question requires a "yes/no" answer. An example is shown below:

**Have you worked at a job or business for pay in the past month?**

- 1  Yes - *Go to 1b*  
2  No - *Skip to 2*

Occasionally, a precoded question may call for multiple entries. In this case, mark (X) all the answer categories the respondent selects. After the respondent finishes, probe to make sure he/she has given all possible answers. Some questions that require additional probes have words such as "*Probe if necessary*" or "If yes ask:" written in italics, followed by the probe written in bold type. An example is shown below:

**Since the period when you were at your physical best, have you experienced any decrease in your ability to carryout your routine activities of daily living such as working, housework, walking, driving, dressing, bathing, and so forth?**

*If "Yes", ask: Would you say that your ability has decreased some or a lot?*

- 1  No, no decrease  
2  Yes, some decrease  
3  Yes, a lot of decrease  
9  DK

In some questions, you must probe for other answers by saying something like "Any others?" or "Anything else?" or something appropriate for the question. For example:

**What problems do you have getting around outside the home?**

**Anything else?**

*Mark (X) all that apply.*

For these questions, you would continue to ask "anything else" until you get a negative response.

## 2. Open-ended Questions

These questions are followed by blank spaces for you to record the respondent's answer. They do not list the possible answers. For example:

**Please tell me each surgical procedure you had and your age at the time of the procedure? Any others?**

Age      99  DK age  
Yrs

Surgical procedure description  
Surgerly to lengthen  
tendons in knee

99  DK surgical procedure

Write the respondent's answer in the space provided.

## 3. Dependent Questions

Dependent questions are asked of only some of the respondents. The determination of who is asked the question is "dependent" upon the response to a previous question. Skip instructions tell you when to omit a question based on a particular answer. For example:

**9a. Do you sometimes have trouble with dizziness?**

- 1  Yes - *Go to 9b*
- 2  No - *Skip to 10*
- 3  DK - *Skip to 10*

**9b. Does dizziness prevent you in any way from doing things you otherwise could do?**

Asking question 9b is dependent upon the response to question 9a. If the answer to question 9a is "No" or "DK", you skip to question 10 and not ask question 9b.

## 4. List Questions

When asking list questions like 3c on page 25 of the DFS-1, you do not need to repeat the lead in, "is this person a -" as long as you get a straight "Yes" or "No" answer. If there is a break in asking the list, repeat the lead-in. The question mark at the end of each category is an indication that you must wait for an answer to each item before asking the next. For this type of question, you will mark all categories that apply.

Question 14 on page 6 of the DFS-4 represents another style of list question. In this example, you will read all categories at once without waiting for an answer to each. This

is indicated by the comma at the end of the category. Mark only one answer in this type of question.

### C. CONVENTIONS AND INSTRUCTIONS IN THE QUESTIONNAIRE

In addition to the questions you ask the respondent, there are instructions to you printed on the questionnaire. They are there to help you use the questionnaire correctly. Some of the more common conventions and instructions in the questionnaire are:

#### 1. **Bold Print**

The questions you ask the respondent or statements you read to the respondent appear in **bold print**. Stress words in all **CAPITAL LETTERS** by speaking slightly louder. An example is shown below:

**How many DIFFERENT times have you been a resident or patient in a nursing home?**

In this question you would stress the word "DIFFERENT" when reading the question.

#### 2. **Words in Light Print and/or *Italics***

Words or phrases in light print and/or *italics* are always FR instructions and are not read to the respondent. For example:

*Mark box if "Now in nursing home"; otherwise, ask:*

**On what date were you discharged (the LAST time)?**

#### 3. **Skip Instructions**

Skip instructions usually follow answer categories and tell you where to go next. In most cases, you will be referred to a specific question. An example is shown below:

**Does (*child*) NOW have bandages changed at home?**

1  Yes (Go to 2b)

2  No (Skip to 13)

If the respondent answered "No" to this question, you would skip to question 13. When an answer is not followed by a skip instruction, simply go to the next question. Or, in the above example, "*Go to 2b*" tells you to go to the next question.

There are also skip instructions above some questions. For example:

*Ask only if box 01 marked in 12a; otherwise, skip to 13 on page 8.*



During the past 12 months, about how much did you or your family pay for your nursing home stay(s)? Do not count any money that has been or will be reimbursed by insurance or any other source.

If box 01 was not marked in question 12a, you are instructed to skip to the next question.

#### 4. Check Items

Check items direct you to the next appropriate question or section by requiring you to refer to previous information and to mark a box in the response column. Check items are not read to the respondent. For example:

<i>Item</i> B2	<i>Refer to child's age on label.</i>	1 <input type="checkbox"/> <i>3 + years old (Go to 3)</i> 2 <input type="checkbox"/> <i>Other (Skip to 4)</i>
-------------------	---------------------------------------	--

Whenever you encounter a check item, complete it before continuing by marking the first box that applies and following the instruction for that box.

#### 5. Words in Brackets

Brackets are used to indicate a choice of words. These words may be either separated by a slash or vertically aligned.

In the example below, you would select the appropriate word from the brackets phrase, depending on how the previous questions was answered.

Where did (child) receive inpatient [mental health/(and) substance abuse] services during the past 12 months?

#### 6. Words in Parentheses in a Question

Occasionally, you will find words or phrases in parentheses as part of a question. In these cases, you have to decide if the word or phrase is appropriate to include in the question based on information reported previously in the interview. An example is shown below:

**(Other than your spouse) [is/are any of] the person(s) living with you 18 years of age or older?**

For this question, you read or do not read the words "Other than your spouse" depending on whether the sample person is married or not.

#### 7. Words in Italics Within Parenthesis and Underlined

These words are instructions for you to insert something such as a name, date, or previous response when asking the question. An example is shown below:

Approximately how many hours was (*child*) cared for by (*answer in 4a*) LAST WEEK?

In this case, insert the sample child's name and the response from question 4a when you ask the question.

#### 8. Zip-a-Tone

**Zip-a-tone** is a band of shading which stretches across an entire page. You should complete the items above these areas before asking the questions below the shaded area. **Zip-a-tone** will usually be found in chart-type questions with multiple answer columns. An example of zip-a-tone shading can be found following question 9 on page 8 of the DFS-1. In this example, you will ask 9c-f across pages 8 and 9 before going to question 10.

### D. RECORDING ANSWERS

If you fail to write down or mark an answer properly, we will not obtain accurate data for the survey. Always record answers in pencil, not pen or marker. Use a pen only to complete the Polio Provider Permission Form on page 23 of the DFS-4 questionnaire. **ERASE** entries made in error. Some general instructions for recording answers are listed below.

#### 1. Recording Precoded Answers

The most common way to indicate the answer given is to mark the appropriate box or boxes. Be sure to keep your "X" in the appropriate box so that there is no confusion about which box you intended to mark.

*Mark (X) all that apply.*

- 1  Child's home
- 2  Home run by organization
- 3  Other private home
- 4  Facility or institution
- 5  Other
- 9  DK

#### 2. Date Entries

Always record the month, day, and year (or month and year) in that order. Use two-digits when recording each part of the date entry. For example, "07/14" for July 14<sup>th</sup>.

#### 3. Number Entries

For some questions, a numerical entry is required. This may be a number of times, days, visits, etc., as in the first example below; or, it may be a dollar amount such as in the second example.

During the past year, on the average, how many days did you drink alcoholic beverages, that is, beer, or wine, or liquor?

2 Days  
(Number)

During the past 12 months, about how much did you or your family pay for your nursing home stays? Do not count any money that has been or will be reimbursed by insurance or any other source.

\$ 1200 .00

Try to get a specific number. Sometimes the respondent may not be able to give an exact number, but may answer in terms of a range or an interval. In such cases, assist the respondent in making an estimate by probing. For example, if the respondent answered "10 to 15 times per year," you would probe by asking, "Could you give me a more exact number?" or "Would that be closer to 10 or 15 times per year?" If the final answer is an interval or range, for example "12 to 14 times per year," record "12 to 14" in the answer space; or, if the best answer you can get is an estimate, note this fact, such as "12 est." (NOTE: This does not apply to questions that request only an estimate: Do not enter "EST" for such. In the above example, the question says, "... about how much ..."; therefore, you do not have to indicate the answer is an estimate.)

#### 4. Rounding Number Entries

Record whole numbers only. If fractions, decimals, or cents are reported, round to the nearest whole number and record that amount. If 50 cents or more or  $\frac{1}{2}$  or more, round up. If less than 50 cents or less than  $\frac{1}{2}$ , round down. (This rule does not apply to ages. Always round fractional ages down.)

5. Written Entries

Certain questions require a written response. Record **EXACTLY** what the respondent says. Do not summarize, paraphrase, or condense the response. Be sure your writing is legible and if at all possible, print the answer. Ask the respondent to spell any information you are not sure of. Use the "Notes" space for answers that are too long to write in the provided space. An example is shown below:

What is the name and address of the hospital to which you were first admitted when you got polio?

- 0  None (Go to 58c)
- 1  Name of hospital/facility

Switland General Hospital		
Address (Number and street) 1012 Main Street		
City/Town Switland	State MD	ZIP Code 20033

- 9  DK

6. Don't Know Responses

Sometimes a respondent may indicate that he or she doesn't know the answer to a particular question. Probe for an acceptable answer. If the person still cannot answer the question, indicate the "Don't know" response by marking the "DK" box if there is one, or writing "DK" in the answer area for that question.

For example:

Has (*child*) received any of these special education services during the past month?

- 1  Yes
- 2  No
- 9  DK

Do you have any special equipment on your car or other motor vehicle because of an impairment or health problem that (*child*) has?

- 1  Yes
  - 2  No
  - 3  Don't have a car
- DK**

## 7. Refused Items

If a respondent refuses to answer a particular question, explain the need to have all applicable questions answered. If the respondent still refuses to answer, enter "REF" in the answer space, as shown below. Do not let a refusal on one question interfere with asking all other appropriate questions.

1a. Does an ongoing health problem, impairment or disability now make it difficult for you to look for work?

- 1  Yes  
2  No  
3  DK
- Ref

## E. PROBING SKILLS

The quality of any interview depends a great deal on your ability to probe meaningfully and successfully. Probing is the technique used to stimulate discussion and obtain more information. Probe when a respondent's answer is not complete or doesn't answer the question.

### 1. Two Functions of Probing

The two major functions of probing are:

- Motivating respondents to enlarge, clarify, or explain an answer;
- Focusing the respondent's answer so that irrelevant and unnecessary information can be eliminated.

### 2. Types of Probes

It is very important to always use neutral probes. You should not imply to the respondent that you expect a specific answer or are dissatisfied with an answer. Under the pressure of the interviewing situation, it is easy to unintentionally imply that some answers are more acceptable than others or to hint that a respondent might want to consider "this" or include "that" in giving responses.

There are several different neutral probes that can be used to stimulate a fuller, clearer response. Examples of neutral probes include:

- **Neutral expressions** - By saying such things as "un-huh" or "I see" or "yes," you indicate that you heard the response, but you expect more.
- **An expectant pause** - The simplest way to convey to a respondent that you know he or she has begun to answer the question, but has more to say, is to be silent. The pause -- accompanied by an expectant look or nod of the head -- allows the respondent time to gather his or her thoughts.

- **Repeat the question** - When a respondent does not seem to understand the question, misinterprets it, seems to be unable to decide, or strays from the subject, just repeat the question. The respondent usually will realize what kind of answer is needed after hearing the question for the second time.
- **Repeating the respondent's reply** - Simply repeating what the respondent said is often an excellent probe. Hearing the response just given often stimulates the respondent to further thought.

### 3. Don't Know Responses

**Accept a "Don't know" response only as a last resort.**

Don't be too quick to accept that response. The don't know response can mean a number of things. If a respondent gives a don't know response, sit quietly, but expectantly, and your respondent will usually think of something further to say. Silence and waiting are frequently your best probes for "don't know." Other useful probes are "Your best estimate will do," or "I just want your own ideas on that."

If you feel the respondent has answered "don't know" out of fear of admitting ignorance, you may reassure him or her by saying, "Would you like to check your records?" or "All answers are correct, so your best estimate/own ideas will be fine."

**Always try at least once to obtain a reply to a don't know response, before accepting it as the final answer.** Be careful not to antagonize respondents or force an answer if they say again that they don't know. In this situation, proceed to the next question after recording the don't know reply.

### 4. Rules of Probing

There are some general rules of probing that will help you avoid biasing respondent answers. These rules include the following:

- Don't ask whether a person means this or that, because it suggests that only one of the two answers is correct. There may be other possibilities that the respondent is thinking about.
- Don't try to sum up in your own words what someone said. This may suggest to the respondent that YOUR idea is the "right answer."
- Don't ask whether the respondent meant a particular thing by a certain word. This suggests an answer, when he or she might actually have another one in mind.

### 5. When to Stop Probing

When you obtain as much information from the respondent as possible and when you have encouraged the respondent to clarify the meaning in his or her own words so that you know exactly what she or he had in mind, only then do you have a complete answer and

only then should you stop probing. However, if at any time the respondent becomes irritated or annoyed, discontinue probing. We do not want the respondent to refuse the rest of the interview.

#### **6. Rewording Questions for Proxy Respondent**

The questions in the DFS-2,3, and 4 all say "YOU", assuming that the **Sample Person** is the respondent. In cases where you must interview a proxy for the **Sample Person**, replace the "You" with the **Sample Person's** name. For example:

**Was Barbara Moore admitted to the hospital at the time she was first diagnosed with polio?**

Certain questions requiring expressions of the **Sample Person's** personal feelings or opinion will not be asked of proxy respondents. For example, proxy respondents will not be asked the following question on the DFS-4 polio questionnaire:

**Which statement best describes how you feel about you physical condition?**

## CHAPTER 5. INTERVIEWING PROCEDURES

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### **A. WHO WILL BE INTERVIEWED**

#### **1. Contacting the Sample Person/Desired Respondent**

During the DFS, you will locate and contact each sample person designated on the questionnaire label. To verify the address and to arrange an appointment to conduct the interview, you may want to call ahead of time. All DFS interviews should be conducted by personal interview; however, if a telephone interview is the only way it can be completed, conduct it by phone.

For sample children, the label on the DFS-1 questionnaire will identify the "desired respondent" (DR). This usually will be a parent or guardian, but may be another care taker. If the desired respondent is not available or not able to answer, interview someone else who is knowledgeable about the sample child. Screening questions on pages 2 and 3 of the DFS-1, DFS-2 and DFS-3 questionnaires assist you in determining who, when, and where to interview. More detail on these screening questions is contained in Chapters 7 and 8.

#### **2. Determining the Sample Person's Current Address**

If the sample person's address printed on the questionnaire is not correct:

- a. **Inquire** - Inquire of current residents, neighbors, building managers, landlords, or a government agency such as the tax assessor's office or town hall. If you learn that the Sample Person has moved, record the new address and telephone number in the "first" New Address space in the screening questions and continue to attempt to make contact.
- b. **Incorrect street names** - You may determine that the street name on the printed DFS label is incorrect. Common errors include minor differences in the spelling of street names, inconsistent directions, and road designations that are not the same. Make such corrections on the label.

#### **3. Locating New Addresses and Telephone Numbers for Sample Persons Who Have Moved**

Since the DFS is a sample person survey, sample persons who have moved must be followed to their new address. You must make every effort possible to locate a sample person who has moved. Remember that in your inquires, you may **NOT** mention that you want to contact the sample person to conduct the DFS. You may only say that you wish to contact him/her for an important survey being conducted by the Bureau of the Census. Sources you might use to locate the sample person are:

- a) **Call Directory Assistance** - Call directory assistance or use local telephone directories to obtain a new telephone number and or/address.



- b) **Contact the Post Office** - Contact the post office which serves the last known address to obtain any change of address information they may have for the sample person or the family.

**NOTE:** The U.S. Postal Service Administration Support Manual, Section 353.323 authorizes the Post Office to provide Census Bureau employees with any information necessary to locate the Desired Respondent.

- c) **Visit the Address Listed on the DFS Questionnaire Label** - Inquire of the persons currently living at the address and of neighbors in the area if they know where the sample person moved or if they have a new telephone number for the sample person.
- d) **Telephone or Visit the Contact Person** - Call or make a personal visit to the contact person listed on the DFS label. The contact person information was obtained during the HIS interview. At that time, we asked the respondent to identify a friend or relative who would be able to help us contact the respondent if he or she moved. Therefore, the contact person should be able to give you an address or telephone number for the sample person, or they may be able to tell you the name/address/telephone number of someone who can provide you with information about the sample person.
- e) **Polk Directories, Criss-Cross Directories** - Use local area directories, criss-cross directories, or other similar sources to obtain a new address or telephone number for the sample person. Local libraries or your regional office may have copies of such directories.
- f) **Public Utilities, Public Assistance, Motor Vehicle Administration** - In some areas of the country, you may be able to obtain change of address information from public utilities, public assistance offices, or a Motor Vehicle Administration office. The amount of cooperation from these types of offices varies from location to location.
- g) **Unable to Locate** - If you exhaust all possible sources and are unable to locate a sample person, call your office and explain the situation. The office may have additional recommendations which could help you locate the sample person. When instructed by your office, return the questionnaire with box 06 - unable to locate marked in Part II. A on the Cover Page.

#### 4. New Address

If the new address is within your assignment area, conduct the interview. If the address is outside your assignment area, or you don't know if it is outside your area or not, call your office. You may be advised to make a personal visit, attempt a telephone interview, or return the case to the office to transfer to another FR. **DO NOT** return a case as an "unable to contact" noninterview unless your supervisor authorizes you to.

**B. PROXY INTERVIEWS**

1. Adult Sample Persons

If at all possible, the sample person should respond for him/herself. It is expected, however, that some sample persons will be unable to respond because of a mental or physical limitation, or because he/she is not available for the entire interviewing period. Whenever that occurs, conduct the interview with a proxy respondent for the sample person. The screening questions on pages 2 and 3 of the DFS-2 and DFS-3 questionnaires will assist you in making these determinations.

2. Sample Child

During the original HIS interview, the respondent was asked to identify the person who knows the most about the sample child's health. This is the "desired respondent" (DR) for the sample child. If the desired respondent is unable to respond, identify a "preferred respondent" in the screening questions on page 2 of the DFS-1 and conduct the interview with that person.

**NOTE:** Neither the sample child nor the spouse of a sample child is an acceptable respondent for the DFS-1 questionnaire. If the sample child or spouse is the only possible respondent, conduct the interview on a DFS-2 questionnaire instead of the DFS-1. Transcribe all label entries to a blank DFS-2 before starting the interview. Return both the labeled DFS-1 and completed DFS-2 together to your office once the case has been finalized.

**C. SUGGESTED INTRODUCTIONS**

Introduce yourself (show your official ID card) and ask to speak to the sample person or Desired Respondent. If a personal visit say:

**(Hello, I'm \_\_\_\_\_ from the United States Bureau of the Census. Here is my identification.) We are conducting a health survey for the U.S. Public Health Service. We spoke with you or someone in your family several months ago and I would now like to conduct a followup interview with you. (May I please come in?)**

When making a telephone contact say:

**(Hello, I'm \_\_\_\_\_ from the United States Bureau of the Census.) We are conducting a health survey for the U.S. Public Health Service. We spoke with you or someone in your family several months ago and I am now calling to schedule to followup interview with you. When would be a good time to visit you?**

If you are unable to conduct an interview at the initial contact, try to schedule a time when you can call back or return for an interview. Begin call back interviews with one of the following introductions:

SP-1st contact:

(Hello, I'm \_\_\_\_\_ from the United States Bureau of the Census. Here is my identification.) We are conducting a health survey for the U.S. Public Health Service and spoke with you or someone in your family several months ago. When I tried to call/visit you recently, I was told that now would be a good time to conduct a followup interview with you.

SP-Other contact:

(Hello, I'm \_\_\_\_\_ from the United States Bureau of the Census. Here is my identification.) We are conducting a health survey for the U.S. Public Health Service and when I contacted you recently, you said that now would be a good time to conduct the followup interview with you.

DR-1st contact:

(Hello, I'm \_\_\_\_\_ from the United States Bureau of the Census. Here is my identification.) We are conducting a health survey for the U.S. Public Health Service and spoke with (you) or someone in your family about (sample child) several months ago. I am now doing a followup interview since you are the person most familiar with (sample child's) health, I would now like to conduct the interview about (sample child) with you.

Proxy-Other contact:

(Hello, I'm \_\_\_\_\_ from the United States Bureau of the Census. Here is my identification.) We are conducting a health survey for the U.S. Public Health Service and when I contacted you recently, you said that now would be a good time to conduct the interview about (sample person) with you.

#### **D. OVERCOMING OBJECTIONS**

If a respondent says that he/she does not wish to participate, stress the following points in your effort to gain cooperation:

- The confidentiality of the survey data is provided by Title 42, United States Code and the Privacy Act. Explain that the primary purpose of the Privacy Act is to serve as a further safeguard to the confidentiality of information supplied by respondents. Assure the respondent that no identifiable information will be released to others without his/her expressed written consent.

- Explain that since the DFS is a sample survey, his/her answers represent many other cases. It is important that we complete interviews for as many sample persons as possible to assure the completeness and accuracy of the final results.
- Explain that the data gathered in this survey will be used to better understand aging disabilities, assist in developing health policy, and determine the availability and use of appropriate health care services. If appropriate, note that it will aid in determining the late effects of polio and its impact on functioning.

**E. PUBLIC RELATIONS**

Often respondents may ask you questions about health care, disease, government programs, etc. Never attempt to answer these questions regardless of how sure you think your information is. Explain to the respondent that you are not qualified to answer such questions and suggest that he/she contact a physician, lawyer, insurance agent, etc. for assistance.

**F. REVIEWING YOUR WORK**

With the Respondent - Look over the completed questionnaire(s) before leaving the respondent (or terminating the phone call). In this way, you can pick up any missing information and avoid a callback.

Also, at this time remind the respondent of any arrangements made for a callback to obtain information that was not available during the interview.

At Home - Carefully review and edit all questionnaires before mailing them to your office. If any errors are found, contact the respondent again (preferably by telephone), and complete the missing information or correct the error. Do not try to provide the missing information or correct the error from memory. If you cannot reach the respondent to obtain the missing information, write a note explaining the situation next to the answer categories for the appropriate questions. Chapter 11 of this manual contains additional editing guidelines.

## CHAPTER 6. THE DFS QUESTIONNAIRES-CONTENT AND INSTRUCTIONS

### A. COVER PAGE

#### 1. Label

A label will be printed on the cover page of the DFS questionnaires. It will contain the name, address, and telephone number of the sample person/child, as well as the contact person's name, address, and telephone number. The labels differ slightly for each questionnaire.

##### a. DFS-1 Label

The following is an example of the information we will provide to help you contact the sample child and complete the interview.

25	941	99801780102	01	1	04356
SC:	Eric W. Cooper			DOB:	07-21-1979
ADD:	1246 Eberhart Street Chicago, IL 60658			AGE:	14
TELE:	(312) 555-7170			SEX:	M
MAIL:	PO Box 25 Chicago, IL 60658				
DR:	Jennifer M. Cooper				
CP:	Shirley Thomas 11034 Stewart Street Chicago, IL 60628				
TELE:	(312) 559-0132				

- 25 - The Regional Office Code
- 941 - The original HIS Sample
- 998 - The HIS PSU
- 0178 - The HIS Segment Number
- 01 - The HIS Serial Number
- 02 - The HIS Person Number of the Sample Child
- 01 - The number of DFS Sample Persons in this household

1      These are numbers for office use only.  
4356

#### 1. SC

The name of the Sample Child as reported in the HIS interview. If the name was refused in the earlier interview, this field may be blank or contain notations such as "Refused", "Child #1", and so on. Use the Date of Birth

(DOB:), age (AGE:), and sex (SEX:) to identify the specific Sample Child when contacting the household. For example, you might say something like: This interview concerns the male born on July 21, 1979. What is his name?

2. ADD

This is the "exact" address reported in the HIS interview. If the unit had a different mailing address, this will be printed after the caption **MAIL: on the label**. If you discover minor errors of these addresses, such as the street name is misspelled or digits being transposed, make the correction on the label. If the Sample Child has moved, however, specify the new address on page 3 of the DFS-1.

3. DR

The "Desired Respondent" is the person reported in the HIS interview as the one who knows the most about the Sample Child's health. This is the person you will try to interview for the Sample Child.

4. CP

This is the name, address, and telephone number of the "Contact Person." During the original HIS interview, the respondent was asked to identify the one person, not in the household, who would always know where the family could be located if they moved. **If you have difficulty locating the Sample Child and/or Desired Respondent, check with the Contact Person for the new address and telephone number.**

b. DFS-2, -3 and -4 Labels

The entries on the DFS-2, -3, and -4 labels are very similar to the one on the DFS-1. The following is an example of the **DFS-2 adult label**.

DFS-2 Label

310	941	99701680103	01	1	04354
SP:	Trenita L. Walton			DOB:	02-13-1939
ADD:	3446 Brothers Place			AGE:	55
	Denver, CO			SEX:	F
TELE:	(913). 379-7922				
MAIL:					
CP:	Betty Bumble				
	327 Sacramento Blvd				
	Denver, CO				
TELE:	(913) 967-8682				

1. The numbers on the top line are examples of:

31	-	The Regional Office Code
941	-	The original HIS Sample
997	-	The HIS PSU
0168	-	The HIS Segment Number
01	-	The HIS Serial Number
03	-	The HIS Person Number of the Sample Person
01	-	The number of DFS Sample Persons in this household

1                    These are numbers for office use only.  
04354

2. SP (Sample Person)

The name of the sample person and his/her exact address at the time of the 1994 quarter 1 NHIS appear next. Whenever possible, we are giving you a complete name for the sample person. However, there may be a few cases where the previous interviewer could not obtain a complete name.

3. MAIL

This is the mailing address at the time of the last interview. It may or may not be the same as the exact address.

4. CP (Contact Person)

This is the name, address, and telephone number of the contact person that we obtained at the time of the last interview. This person should know how to contact the sample person.

5. DOB

This is the date of birth of the sample person.

6. AGE

This is the age of the sample person at the time of the 1994 HIS interview.

7. SEX

To identify the specific sample person when contacting the household.

8. TELE

This is the telephone number of the sample person.

The entries on the DFS-3 and DFS-4 are very similar to the DFS-2. The only difference is to the right of the "Number of sample persons in Household" on the DFS-3 label, there is another one-digit number from 1-6. This is used by your office to select cases for a special telephone test in certain areas of the country. If you are working on this test, your office will give you a DFS-100T manual with special instructions.

The DFS-4 questionnaire will be administered to persons who reported having had polio in the original HIS interview. In most cases, these polio survivors will be interviewed on a DFS-2, or -3 questionnaire; however, there may be some who will get only the DFS-4. In the event you happen to get a DFS-4 without a DFS-2, you will need to make some adjustment in your initial introductions. There are no screening questions in the DFS-4. Ask to speak to the Sample Person, and if that is not possible, identify a knowledgeable proxy respondent the same as you would do for the DFS-2 or DFS-3.

If the respondent report a different address or telephone number than what is recorded on the label, record the new information in "Part III - New Address" in the space provided on page 2 of the DFS-4.

## 2. Part I - Call Record

- Use this space to record every attempt to interview or locate the sample person. If you need more space than is provided in this section, continue in the "Notes" section at the bottom of the page.
- Use one line for each attempt to contact the sample person and the contact person. Use the "Results" space to indicate the outcome of the contact. For example: "No one home", "Partial interview", "Complete interview", "Contact person provided new address", etc. Use the "Comments" space to report problems encountered, appointments, and so forth. Record all telephone attempts, except those that do not result in contact with the sample person, such as busy signals, ring-no answer and wrong numbers. Always use two digits for the month and day.
- When entering the beginning and ending times, be sure to circle "a.m." or "p.m." as appropriate. Also enter any comments you may have to explain your attempts.
- Circle "T" for telephone or "P" for personal visit, for each contact/attempted contact.

## Part II - Status

1. A - Final Status - Complete the Final Status of the interview as follows:
  - a. Interview



1. Complete - mark box 01 if the interview was completed, even if some items were refused or DK.
  2. Partial - mark box 02 if you completed only part, but not all of the questionnaire. Do not mark this if only some items were refused or DK.
- b. Noninterview
3. SP refused - mark box 03 if the SP refused to participate in the interview. Enter the reason for the refusal in the Notes space.
  4. Proxy refused - mark box 04 if a proxy refused to participate in the interview.
  5. Unable to contact - mark box 05 if after repeated attempts, you are unable to contact the sample person or an acceptable proxy. Do not return a questionnaire with this box marked until advised to do so by your office.
  6. Unable to locate - mark box 06 if you have exhausted all means of locating the sample person/respondent. Do not return a questionnaire with this box marked until advised to do so by your office.
  7. Deceased - mark box 07 if the SP/SC is deceased.
  8. Institutionalized, no proxy - mark box 08 if the SP is institutionalized and a proxy respondent was not available. Explain the situation in the Notes.
  9. Incapable, no proxy - mark box 09 if the SP is incapable of responding and a proxy was not available. Explain the situation in the Notes.
  10. Moved o/s PSU, unable to phone - mark box 10 only when instructed to do so by your supervisor. If you are unable to contact the sample person because the sample person does not have a telephone AND the person lives outside of a current PSU (personal visit not possible), explain the situation in the Notes section. Record the new address in Part III. Notify your supervisor of these situations before marking this box and returning the case to the regional office, since the case may be reassigned to another interviewer or another RO.
  11. Other noninterview - mark box 11 if none of the above boxes apply. Describe the situation completely in the "Notes" space and return the case to the regional office.

2. B-Mode - The mode indicates how the final status was determined. Mark "Telephone" if the interview was completed or final noninterview status was determined by telephone. Mark "Personal visit" if the interview was completed or final noninterview status was determined by personal visit.
3. C-Respondent - Mark the appropriate mark to indicate whether the interview was completed by the sample person or a proxy respondent. If a proxy respondent, mark the appropriate box to indicate the reason for a proxy.
4. D-Proxy - If the interview was conducted with a proxy respondent, record the proxy's name and relationship to the sample person in the space provided.

### Part III - New Address

If the Sample Person/Sample Child moved from the address on the questionnaire label, enter the "final" new address in this space. This may be exactly the same as the new address recorded on page 3 or it may be different. For example, if you were told that the Sample Person moved to 1492 Columbus Ave, you record that on page 3 and attempt to contact him/her there. However, if you are then told the Sample Person again moved to 1066 Hastings Street, you record that also on page 3. Record in "Part III - New Address" the address where you finally locate the Sample Person, be it "1066 Hastings Street" or something different.

## CHAPTER 7. DFS-1 CHILD'S QUESTIONNAIRE

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### BACKGROUND

The data collected in the DFS-1 questionnaire will be used to address the issues of children doing without much needed services, the services which are and are not covered by insurance, failure to get services to children who are entitled by law to have them, and the frequency of service usage.

This survey also examines the effect that childhood disabilities have on family members and other caregivers. The data collected will help determine if families and caregivers have adequate support, services and training with which to aid the child.

### INITIAL SCREENING QUESTIONS

The initial screening questions will determine if the interview can be conducted with the person identified as the "Desired Respondent." If the "Desired Respondent" is not available or is incapable of being interviewed, a preferred respondent will be identified. It is of utmost importance to identify and interview the adult who is most knowledgeable about the sample child.

### Instructions

1. If the desired respondent will be available before your closeout date, make arrangements for a callback and footnote the arrangements in the notes space on the cover page.
2. If the desired respondent (and sample child) has moved, attempt to obtain the new address. Record this information carefully and legibly on the first "new address" block of page 3. Conduct the interview at the new address if it is in your normal assignment area; otherwise, call our office for instructions.
3. If the desired respondent and sample child have moved but the respondent to these screening questions cannot give you a new address, mark "DK" in 7b, but do not accept this as a final noninterview until you have exhausted all means of locating them.
4. Read the parenthetical in question 8a the first time it is asked. If there is no relative living with the sample child who could respond, repeat question 8a without the parenthetical.
5. If the sample child is emancipated and living on his or her own, does not have related adult supervision, or if you are told that Preferred Respondent is the sample child or his or her spouse, do not conduct the DFS-1 interview.

In this situation, carefully transcribe all the label information from the DFS-1 to a blank DFS-2, and treat the sample child as any other adult sample person.

Do not destroy the unused DFS-1, clip it to the DFS-2 once you have completed the DFS-2 interview and ship them to the RO together.

6. All DFS-1, 2, and 3 interviews should begin with Item A near the bottom of page 2. The sample person may have had a birthday since the HIS interview, or the age may have been keyed or recorded incorrectly. Therefore, always verify the sample person's age and make corrections, if necessary, right on the label.

## SECTION A. HOME CARE SERVICES

### OBJECTIVE

The purpose of Section A. Home Care Services is to collect information about extra assistance children require at home.

### CHECK ITEM A1 - QUESTION 3

#### A. Objective

The questions in Section A concern special help and supervision the child receives which go above and beyond the kinds of help and supervision most children receive in a normal, everyday situation. We are interested in help and supervision only when the child requires **significantly** more help or supervision than other children his/her age.

#### B. Instructions

1. Read the introduction above Item A1. Insert the sample child's name for "(child)".
2. Fill Check Item A1 based on the child's age as it appears on the label, including the corrected age if changed during the screening questions.

### QUESTIONS 4-8

#### A. Objectives

Questions 4 through 8 obtain information about help provided to a child by family members, friends, volunteers, and paid professionals other than physical therapists and occupational therapists. This information will give analysts an indication of the kinds of help people get and the cost of that help.

#### B. Definitions

Physical therapist--A health care professional who administers therapy to develop or work on gross motor skill movements, such as walking.

Occupational therapist--A health care professional who works to develop fine motor skills usually involving the use of the fingers, hands, or arms. It may involve working on things like dressing, eating, and writing.

Unpaid volunteer--Someone who receives no monetary payments for helping, but is not simply a friend or neighbor.

Paid employee of an organization or business--The helper is paid by an organization or business. The family may pay the organization/business for this help, but does not pay the helper directly.

Paid employee of yours--Fee for service is paid directly by the family to the provider.

Medicaid--Refers to a medical assistance program that provides health care coverage to low income and disabled persons. The Medicaid program is a joint federal-state program which is administered by the states.

Rehabilitation Program--The process of restoring persons with disabilities to the highest level of functioning of which they are capable. The process involves the delivery of a wide variety of goods and services needed by such individuals.

VA Program--Any Department of Veteran Affairs (VA) program which provides medical assistance to veterans, (particularly those with service connected ailments) or their families. It may include:

CHAMPUS--(Comprehensive Health and Medical Plan for the Uniformed Services) provides health care in private facilities for dependents of military personnel on active duty or retired for reasons other than disability.

CHAMPVA--(*pronounced* Champ V-A) (Comprehensive Health and Medical Plan of the Veterans Administration) provides health care for the spouse, dependents, or survivors of a veteran who has a total, permanent service-connected disability.

Other military--Health care programs other than the VA's, available to active duty personnel, retirees, and their dependents.

Pay for therapy during the past 2 weeks--Refers to what the family paid or will pay for the therapy the child received during the past 2 weeks, regardless of when the payments are made.

Past 12 months--Refers to the 12 months prior to the interview date.

Past 2 weeks--Refers to the 14 days prior to the interview date.

### C. Instructions

1. Record up to four names in Table H on pages 6 and 7. If exactly four Helper columns are filled in Table H, ask question 4b to determine if there are more than four helpers. If you do not fill all four helper columns in Table H, skip 4b-d and begin completing the table by asking 5a on page 6 for the first helper.

Include parents and other family members as helpers. Do not include physical or occupational therapists.

The helper's name on Table H is for your reference only. You need not enter a complete name or title: enter whatever the respondent reports.

2. Ask questions 5 through 8, as appropriate, separately for each helper listed.
3. Question 6a asks if help is paid for. This payment includes money from any source, not just parents or other family members. If the respondent does not understand what is meant by paid help, read the categories in 6b as examples.
4. Ask question 6c only if more than one source of payment is marked in 6b. If only one source of payment was reported, transcribe the two-digit number in front of the source in 6b into the answer boxes in 6c.
5. Ask 6d only if a parent or other family member living in the child's household is a source of payment for the help the child receives. If no family member in the household paid for the help, skip to 6f.
6. Since questions 6d and 6e ask "about how much", it is not necessary to probe for an exact dollar value. However, you should probe for a better estimate before accepting a "DK" response. Record only dollar values.
7. After completing 5-8 as appropriate for each helper, skip to Check Item A3 on page 8.

## QUESTIONS 9-12

### A. Objectives

Questions 9 through 12 will supply analysts with information about the frequency of use of respite care, the amount of time a child spends in respite care, and the place where respite care is most often provided.

### B. Definitions

Respite Care--Care provided by a person or organization to relieve the parent or family caregivers. Respite care may be provided at the child's home, someone else's home, a home run by an organization, a facility or an institution. It can be for a few hours or a few days.

### C. Instructions

1. Respite care includes any type of care provided with the purpose of giving the parent/main caregiver a chance to "go out, take a break, or go on a vacation". This could include care provided by a family member, friend or organization.

2. When asking question 9b, include the parenthetical "additional" if respite care was used in the past 12 months (Yes in 9d). Do not include the parenthetical if "No" or "DK" were marked in question 9a.
3. Ask 9c to determine who provided the respite care in the past 12 months. Then for each "yes" in 9c, complete 9d-f, inserting the description of the provider from 9c.
4. In question 12, category 00 - "Did not try to get home care service" and Category 12 - "No problem getting help" are not on Flashcard C4. Do not read these categories in a telephone interview.
  - If the respondent simply answers "No" to question 12, probe to determine whether category 00 or 12 applies.
  - If when reading the categories the respondent answers "No" to each, probe to determine whether they did not try to get services or had no problems. Then, mark 00 or 12 as appropriate.
  - Mark all that apply for categories 01-11, but do not mark 00 or 12 if any other answer is marked.



## SECTION B. WORK/CHILD CARE

### OBJECTIVE

The questions in Section B Work/Child Care are asked to determine child care arrangements if the respondent worked or attended school. These questions will provide analysts with information about the amount of time children spend in child care.

### INSTRUCTIONS

Ask the questions in this section of the respondent even if the respondent is not the primary caregiver or the desired respondent.

### QUESTIONS 1a-B2

#### A. Definitions

Job--A job exists if there is a definite arrangement for regular work for pay every week or every month. This includes arrangements for either regular part-time or regular full-time work. A formal, definite arrangement with one or more employers to work a specified number of hours per week or days per month, but on an irregular schedule during the week or month is also considered a job.

Business--A business exists when machinery or equipment of substantial value in which the person has invested capital is used by him/her in conducting the business; and/or an office or store, or other place of business is maintained; and/or there is some advertisement of the business or profession by listing it in the newspaper, or yellow pages, or through signs, or cards.

Past month--Refers to the 30 days preceding the interview.

### QUESTIONS 3-4

#### A. Definitions

School--Public or private institutions at which students receive formal, graded education. Also include nursery and preschools and schools for the handicapped or mentally retarded where students are not working toward a degree or diploma.

Day Camp--Include any schools/camps that provide programs used as day care.

#### B. Instructions

1. Read the parenthetical in question 3 only for younger children, about 3 to 6 years old. read the parenthetical in question 4a only if "yes" is marked in 3.

2. Mark only one answer in question 4a. If the respondent gives more than one answer, probe for the one that cared for the Sample Child most often during the past month.
3. The relationships in the 4a answer categories may or may not apply to the respondent. For example, if the respondent is the child's mother and works only when the child is in school, mark Box 01. Likewise, if the respondent is not the child's mother, but reports that the mother works only while the child is in school, mark Box 1 also.
4. Although 4a answer category says "work", it applies also to school. For example, if the respondent (mother) goes to school instead of working and says that she only attends school while the child is also in school, mark Box 01.
5. Question 4a answer category 04 may be a sensitive topic, particularly for younger children. If the respondent hesitates or appears reluctant to answer question 4a, assure him/her of the confidential nature of the responses.
6. Questions 4f and 4g apply only to the respondent. Mark "No" in 4f if the respondent does not pay for child care. In 4g, ask for the respondent's satisfaction with the child care arrangements.

## SECTION C. MEDICAL SERVICES

### A. Objective

The objective of Section C is to determine the types of medical care the child received in the past 12 months.

### B. Definitions

Counseling/Mental Health Therapy--Services provided by qualified social workers, psychiatrists, psychologists, guidance counselors or other qualified personnel to help improve the child's state of mind.

Consultation--A visit to get any kind of advice or opinion from a medical professional. This includes advice on problems that may or may not be medical problems, such as the child having problems getting along with teachers and other children at school.

Hospital Emergency Room--Emergency care facility at a hospital. Do NOT include emergency care received at a clinic or HMO. Include emergency room visits which resulted in admission and inpatient care.

Regular Basis--Set intervals for a given period of time such as twice a week for 2 months.

### C. Instructions

"Treatments at a hospital" for question 4 includes both inpatient and outpatient treatments as long as they were administered more than once during the past 12 months. If necessary, read the examples below question 4, but make sure the respondent understands that these are only examples. Any other regular treatments received at a hospital should also be included.

## SECTION D. ASSISTIVE DEVICES AND TECHNOLOGIES

### A. Objectives

Section D obtains information on the type of medical devices, supplies and, implants the child may have.

### B. Definitions

Tracheotomy tube - a tube to facilitate breathing which is inserted into a surgical incision made in the trachea (windpipe) in the front of the neck.

Respirator - a machine that provides artificial respiration, does the breathing for the child or assists in pulmonary ventilation (helps the lungs with breathing) or otherwise serves to alter the air that is breathed through it (e.g., gives air a higher oxygen content, etc.).

Ostomy bag - a receptacle (bag) covering an artificial opening in the abdominal (stomach/intestinal/bladder) area that collect the contents of the bowels (feces) or urinary system (urine) on the outside of the body.

Catheterization equipment - any instruments used to remove body fluids, usually urine, and the equipment used in the process of inserting, removing, or cleaning catheters.

Glucose monitor - any device used in the process of determining glucose (sugar) concentration levels in the blood or urine. It assists in reading re-agent test strips that have been dipped in blood or urine by providing color matching charts, or, if electronic, may actually produce a number value.

Diabetic equipment/supplies - any instruments used to deliver insulin to the body including insulin pumps, syringes, needles, sterilization equipment, etc.

Inhaler - an apparatus for delivering vapor (steam) or vaporized medication directly into the lungs by breathing or specifically, an apparatus to help children breath.

Nebulizer - a machine that sprays air through a tube attached to a cup to which liquid medicine has been added so a child can breath the medicine directly into the lungs.

Scooter - a motorized vehicle used in lieu of a wheelchair.

Ear vent tube - a small tube surgically placed through the eardrum to equalize air pressure between the outside and the inner ear. Usually left in until they fall out on their own.

Shunt - a tube surgically inserted inside the body that diverts fluid (or allows it to pass) from one place to another within the body.

Artificial joint - a man-made, surgically implanted replacement for any of the joints of the body, but most commonly finger joints, wrists, knees and hips.

Implanted lens - part of the eye from a donor person or an artificial lens that is surgically inserted into the eye of someone whose lens has been damaged or is diseased, to improve their sight. It is sometimes called an intraocular lens.

Implanted pin, screw, nail, wire, rod, or plate - man-made objects surgically inserted into the body to help provide support for any of the bones including the skull.

Artificial heart valve - a man-made, surgically implanted replacement for any of the mitral, aortic or tricuspid heart valves.

Pacemaker - a man-made device surgically inserted into the body that mechanically or electrically changes the rate at which things happen, usually heart rate.

Silicone implant - material surgically inserted into the body that is made of silicone (a man-made synthetic).

Infusion pump - a device that injects a pre-measured amount of fluid (other than blood) into the body during a specific interval of time.

Cochlear implant - a device surgically implanted in or near the inner ear accompanied by a device worn externally to improve the child's hearing. It is not removable, as is a hearing aid. Pronounced: *kōk'le-er*

Organ transplant - any organ or tissue that is taken from the body and either implanted into another area of the same person's body or into another individual.

### **C. Instructions**

1. Ask question 1a-o before asking question 2. Then, ask question 2 for each "Yes" in question 1.
2. Question 1 include the use of the devices and supplies in the past 12 months, not necessarily the purchase during that period. For example, a wheelchair used in the past 12 months may have been obtained years earlier.
3. Question 3 concerns the total cost to the family in the past 12 months for all devices used. This includes such things as purchase/installation price, rental fees, repair fees, maintenance costs, and so forth. Get the respondent's best estimate.
4. Question 4 includes only implants the child currently has. For example, do not include ear vent tubes a teenager had when he/she was 4 years old.

## SECTION E. OTHER SERVICES

### A. Objective

The questions in Section E concern services a child received in the past 12 months from a variety of therapists, nurses, attendants, and other professionals.

### B. Definitions

Physical therapist--A health care professional who administers therapy to develop, improve, or restore gross motor skill movements, such as walking.

Occupational therapist--A health care professional who works to develop, improve, or restore fine motor skills and usually involves the use of the fingers, hands, or arms. It may involve working on activities like dressing, feeding, and writing.

Audiologist--A person skilled in working with hearing problems. These services include: identifying a hearing problem; determining the range and nature of the hearing problem; training the child to deal with the problem, such as teaching lip-reading; and counseling the child's parents, teachers or other family members on how to deal with the problem.

Speech therapist or pathologist--A person who works with someone to improve speech or oral communication for problems such as stuttering, impaired articulation, or a language or voice impairment.

Recreational therapist--Includes art, music or dance therapy, as well as evaluating the child's leisure and recreational activities, participation in school and community activities and/or providing leisure education.

Visiting nurse--A nurse who provides services for the child in the child's home.

Personal care attendant--A paid individual whose main responsibility is providing assistance and nonmedical care to the child, including help with eating, bathing, dressing, etc.

Reader or interpreter--Someone who is paid to read, sign, or in other ways interpret communications for the child.

Services from a center for independent living--Include such things as peer counseling, employment counseling, help with accommodations at home, work, or in transportation, recreation services, advocacy services, and assistance in obtaining or using assistive technology (see Section D).

Respiratory therapy services--Those services that are prescribed by a physician for the assessment, diagnostic evaluation, treatment, management, and monitoring of patients with deficiencies and abnormalities of cardiopulmonary function.

Social work services--These would include preparing a development history for the child; group and individual counseling with the child and/or his/her family; helping to work out daily living situations for the child that affect home, school and community; and helping the child and family to utilize school and community resources.

Transportation services--This includes transportation provided for the child by the school system, community, or other group, NOT transportation provided by the parents or parent arranged car pools. It is transportation to and from school; travel in and around school; and the use of special buses or vans adapted with lifts or ramps. It does not include normal school provided buses used by all children.

Private health insurance-- any type of health insurance (other than public programs), including coverage by a health maintenance organization (HMO) AND single service plans.

Medicaid--See manual page 7-4.

Rehabilitation program--See manual page 7-4.

VA program--See manual page 7-4.

Other military--See manual page 7-4.

### C. Instructions

1. Complete questions 1-5 as appropriate for each service before asking questions 1 through 5 for the next service.
2. Record in question 3b, the two digit number of the main source of payment from 3a. If there is only one source of payment in 3a, transcribe the two digit number without asking question 3b.
3. Ask questions 3c and 3d only if payment for services comes from a parent or other household family member as marked in 3a.
4. For "(Month)" in question 4, insert the month prior to the one in which the interview is being conducted. For example, for interviews in October, ask about services received in "September".
5. After reading question 6a in a telephone interview (or when the respondent cannot or will not read the flashcard), immediately read the answer categories in 6b and mark each "yes". If any boxes are marked in 6b, mark "yes" in 6a. If no boxes are marked in 6b (meaning the child is not on a waiting list), mark "no" in 6a.

## SECTION F. EDUCATIONAL SERVICES

### A. Objective

Section F concerns special education services, as defined in 1a and 5a.

### QUESTION 1a

### B. Definitions

Transportation services--See page 7-13.

Speech/Language therapy--Includes work with someone to improve speech or oral communication for problems such as stuttering, impaired articulation, or a language or voice impairment.

Audiology services--See page 7-12.

Mental health or counseling services--Mental health services provided by qualified social workers, psychiatrists, psychologists, guidance counselors, or other qualified personnel which are intended to improve a child's state of mind.

Developmental testing--Administering psychological and/or educational tests, and other assessment procedures.

Physical therapy--See page 7-13.

Occupation therapy--See page 7-13.

Recreational therapy--See page 7-12.

Respiratory therapy--See page 7-12.

Social work services--See page 7-13.

Eyeglasses--Does not include contact lenses, but does include glasses for special conditions such as cataracts. Does not include non-prescription glasses, such as sunglasses or safety glasses.

Other assistive devices and related services--Any item, piece of equipment, or system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of children with disabilities. Services for these include evaluation of the needs of the child; purchasing, leasing, or providing the assistive device; selecting, designing, fitting, adapting, repairing, or replacing



the device; coordinating and using other therapies, interventions or services with the assistive device.

Medical services--Services provided by a licensed physician to determine a child's medically related disability that results in the child's need for special education and related services.

Communication services--These services involve the use of an interpreter who reads or signs for the child.

Nursing services--This includes the assessment of health status for the purpose of providing nursing care; provision of nursing care to prevent health problems, restore or promote functioning; administration of medications, treatment, and regimens prescribed by a licensed physician.

Learning disability--A disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written. It may be evident by an inability to listen, think, speak, read, write, spell or do mathematical calculations. It includes conditions such as brain injury, minimal brain disfunction, dyslexia or aphasia. It does not apply to children who have difficulty learning as a result of visual, hearing, motor, mental retardation, or emotional disturbance.

Speech or language problems--Communication disorders such as stuttering, impaired articulation, a language impairment, or a voice impairment.

Mental retardation--Significantly below average in intellectual functioning along with problems in adaptive behavior.

Emotional disturbances--A condition exhibiting one or more of all the following characteristics over a long period of time: an inability to learn that cannot be explained by intellectual, sensory, or health factors; an inability to build or maintain interpersonal relationships with peers and teachers; inappropriate types of behavior or feelings; pervasive mood of unhappiness; tendency to develop physical symptoms associated with personal or school problems. This includes schizophrenia. It does not include children who are socially maladjusted unless it has been determined that it is severe enough to meet the aforementioned criteria.

Deaf and blind--Means both hearing and visual impairments, which cause severe communication and other developmental and educational problems.

Orthopedic problem--A severe musculoskeletal impairment.

Autism--A developmental disability significantly affecting verbal and nonverbal communication and social interaction.

Traumatic brain injury--An acquired injury to the brain caused by an external force, resulting in total or partial disability.

Developmental delay--Significantly delayed, as defined by the state and measured by appropriate diagnostic tests in one of several areas: physical development, cognitive (mental) development, social or emotional development, or adaptive development.

Multiple disabilities--A combination of impairments such as mental retardation and blindness, which causes such a severe educational problem that the child cannot be accommodated in special education programs for just one of the impairments.

Other health problems--Chronic or acute health problems such as a heart condition, tuberculosis, rheumatic fever, epilepsy, lead poisoning, leukemia, etc., that adversely affect the child's educational performance.

**C. Instructions**

1. Read the introduction to question 1 carefully before asking the question.
2. Include as special education programs which are paid for by the public school system, including a variety of services that may or may not take place in school.
3. The "Deaf and Blind" category in question 1c is not meant to overlap with the "hearing" or "visual" categories. If a child qualifies as "Deaf and Blind", do not also mark the "Hearing" or "Visual" categories. Deaf and blind disability requires a separate program where the child's needs cannot be met in either visual or hearing single disability programs.
4. The "Multiple Disabilities" category in question 1c is not meant to overlap with any other category. If a child qualifies as having "Multiple Disabilities," do not mark any other specific disability. Multiple disabilities requires a separate program where the child's needs cannot be met in any program for a single disability.
5. Past month, the reference period in questions 1e and f, refers to the past 30 days.

**QUESTIONS 2-4**

**Instructions**

1. Ask question 2 only for children over the age of 16.
2. Category "00"-No problem getting services of question 3d appears on the questionnaire, but not on Flashcard C7. Do not read the category to the respondent in a telephone interview, but mark it if it is the respondent's answer to question 1d.
3. Question 4 applies only to the respondent's opinion. If you get some other's opinion in the response, repeat the question, emphasizing "You".

4. Question 4 is asked for all children 3+ years old regardless of whether or not they receive special education services or any educational services at all. For example, a 3 or 4 year old (or 17 year old) may not be receiving any educational services. This question concerns whatever educational services they receive, not just special education.

## QUESTIONS 5-7

### A. Definitions

Family training, counseling and home visits--Services provided by social workers, psychologists, and other qualified personnel to assist the family of a child in understanding the special needs of the child and enhancing the child's development.

Nutrition services--Includes conducting assessments of nutritional history, biochemical and clinical variables, feeding skills and feeding problems, and food habits and preferences. It also includes developing and monitoring the nutritional needs of the child, making diet plans, and making appropriate referrals to community resources.

Psychological services--Includes administering psychological and developmental tests; interpreting the results of tests; obtaining and assessing information about the child's behaviors and child and family conditions related to learning; developing and managing a program of psychosocial services, including counseling for the child and family, parent training, and education programs.

Case management--The coordination of personal care and social or medical services for persons with special needs.

Special instruction--Includes the design of a learning environment and activities that promote the child's acquisition of skills in a variety of developmental areas; curriculum planning including the interaction of personnel, materials, and time; providing the family with information, skills, and support related to enhancing the development of the child; and working with the child to enhance the child's development.

Early intervention services--Designed to meet the needs of each child and his/her family related to enhancing the child's development.

### B. Instructions

1. Read the introduction to question 5 carefully before asking the question.
2. Category "00"-No problem getting services of question 6d appears on the questionnaire, but not on Flashcard C7. Do not read the category to the respondent a telephone interview, but mark it if it is the respondents answer to question 6d.
3. Question 7 applies only to the respondent's opinion. If you get some other's opinion in the response, repeat the question, emphasizing "you".

4. Question 7 is asked for all children 3+ years old regardless of whether or not they receive special education services or any educational services at all. For example, a 3 or 4 year old (or 17 year old) may not be receiving any educational services. This question concerns whatever educational services they receive, not just special education.

## SECTION G. COORDINATION OF SERVICES

### A. Objective

The families of children with special needs often require assistance with the coordination of medical and non-medical services. The questions in this section identify and describe such coordination of services, be they performed by professionals or family members.

### B. Definitions

Coordinating--For medical care it involves keeping track of doctors, treatments and medications. For non-medical care it involves social services, personal care services, transportation services, etc.

Medical care--Care provided by a licensed health care professional which could include a nurse practitioner, physician's assistant, or nurse.

Non-medical care--Services which may be recommended by, but do not directly involve licensed health professionals. They include such things as social services, recreation services and transportation services.

Social worker--An individual who prepares a development history for a child; conducts group and individual counseling with the child and his/her family; helps work out daily living situations for the child that effect home, school, and community; and helps the child and family to use school and community services.

Hospital discharge planner--An employee of a hospital who assists in planning and coordinating a child's care after his/her release from the hospital.

Case manager--An individual who coordinates personal care and social or medical services for persons with special needs.

### C. Instructions

1. Multiple responses are acceptable in question 3c because there may be multiple coordinators or a single coordinator may have multiple titles. This concept applies also to 2b and 4b.
2. Refer to page 6-10 for instructions on how to complete question 6.
3. "You" in questions 7, 8, 9, and 10 refers to the respondent. Do not change the wording of the questions even if you were unable to interview the desired respondent.

## SECTION H. PHYSICAL ACTIVITY

### A. Objective

These questions identify the physical activity level of sample children.

### B. Definitions

Physical education--Education programs involving physical activity or sports.

Recreation Programs--Programs or classes involving recreation, hobbies, fun or enjoyment.

### C. Instructions

1. Category 0 - "Did not try to find programs" and category 5 - "Not prevented or limited for any of these reasons" do not appear on Flashcard C10. Do not read either of these categories in question 2 when conducting a telephone interview. However, mark these boxes if that is what the respondent says in response to the question.
2. Read the parenthetical "outside of school" in question 4 if the sample child is of school age. School does not need to be in session at the time of the interview for the child to be "in school".
3. Questions 2-5 may not appear to apply to very young sample children. If this is the case, mark Box 0 in question 2, and "No" in the other questions; however, ask each of the questions as worded or verify the negative responses with the respondent before marking these boxes.

## SECTION I. PERSONAL ADJUSTMENT AND ROLE SKILLS (PARS)

### A. Objective

Section I - Personal Adjustment and Role Skills measures the child's psychological adjustment. These questions are asked only of children 6 and older.

### B. Instructions

1. Read all answer categories when asking question 1a. Repeat them as necessary thereafter. For example, repeat the phrase, "Would you say" with the answer categories if the respondent gives inappropriate responses, such as "yes", "no", and so forth.
2. Repeat the lead-in phrase, "During the past 30 days, has (child) ..." where printed (with 1h, 1o, and 1v) and whenever there is a break in the continuity of the questions, such as when the respondent explains or expounds on a response rather than answering with one of the required answers.
3. If the respondent cannot answer a particular question, write "DK" in the answer space for that question. For example, enter "DK" if the respondent is not familiar enough with how the child spent his/her time in the past 30 days to answer question 1a.
4. The answer categories are not absolute. For example, the child did not have to have been with friends 24 hours a day for 30 days to answer "always" to question 1a. The exact definitions of the answer category, however, are respondent-defined.
5. Do not try to define any of the terms in Section I. If the respondent questions any terms, say simply, "It is whatever you think it means." If this is not sufficient, enter "DK" and footnote the situation.

## SECTION J. IMPACT ON THE FAMILY

### A. Objective

Section J identifies the effects a child's illness or disability has had on the family.

### B. Instructions

1. If two or more family members report changing hours of work in 1b, refer only to the one who changed hours of work most recently.
2. Be sure to emphasize the different time periods in these questions. Question 1a refers to EVER, whereas questions 2 and 3 are only concerned with the past 12 months.



## SECTION K. MENTAL HEALTH

### OBJECTIVE

Section K collects information about the mental health or substance abuse services the child may have received. These are divided into "Inpatient" (1-2) and "Outpatient" (3-4) services.

### QUESTIONS 1-2

#### A. Definitions

Inpatient services - Services received as an overnight patient in a hospital or residential care facility.

Residential Treatment Center - A treatment center (not a hospital) where the patient lives temporarily while receiving assistance in recovery from substance abuse or treatment for mental health problems.

#### B. Instructions

1. If the respondent questions what you mean by "other place" in question 1a, read the answer categories in 1c as examples.
2. Question 1d concerns total admissions in the past 12 months and question 1e refers to total nights for these admissions.
3. Ask question 2f if more than 1 box has been marked in 2e. If only one box was marked, transcribe the two digit number in front of the category into the answer boxes in 2f without asking.
4. Ask 2g if a parent or other household family member has paid for inpatient services as marked in 2e.
5. Refer to page 7-5 for instructions on completing question 2e-g.

### QUESTIONS 3-4

#### A. Definitions

Outpatient services - Medical or counseling services for which the patient is not admitted overnight.

Emergency Basis - Immediate care usually due to a life crisis.

HMO - Health Maintenance Organization - A health care plan that delivers comprehensive, coordinated medical services to enrolled members on a prepaid basis. A HMO differs from other health insurance because it directly provides its members with most or all of their health care while traditional insurers simply process the claims. A HMO assumes responsibility for providing the treatment as well as paying the bills.

**B. Instructions**

1. Question 1d concerns the number of admissions for overnight care due to a mental health or substance abuse problem. Question 3e, on the other hand, concerns the number of months a child received outpatient care.
2. Question 1e refers to nights spent in inpatient care, whereas 3f refers to the total number of times a child received outpatient care.
3. "Family" in 2g refers only to family members living in the same household as the sample child.
4. Complete 4e-g in the same manner as previous similar question (see page 7-5).
5. Include the costs for prescriptions in 4e-g.

**ITEM K4 - QUESTION 9**

**A. Definitions**

Community support--A program that makes available mental health, health, social and support services based on individual need, provided through publicly funded means.

Inpatient - Treatment overnight in a hospital or residential facility.

Outpatient - Treatment which does not involve an overnight stay in a hospital or residential facility.

Past month - refers to the past 30 days.

**B. Instructions**

1. Emphasize to the respondent that the reference period for question 7 changed to the past month, and back to the past 12 months for questions 8 and 9.
2. If the answer to question 6 is simply "yes", ask: "Which, mental health or substance abuse services?" Mark Box 1, 2, or 3 based on the response to this probe.
3. Unlike similar questions category 00 - "Did not try to get mental health services" during the past 12 months appears on flashcard A12 and should be read to the respondent during telephone interviews.

## SECTION L. HOUSING AND TRANSPORTATION

### A. Objective

Section L identifies modifications or special features in housing and transportation needed by the child due to a physical impairment or other health problem. When combined with other information, they will help identify housing and transportation features which do or do not contribute to a "barrier-free" environment.

### B. Definitions

Bathroom modifications - Include modifications that assist a child with special needs, such as a raised toilet seat, grab bars near the toilet, a tub stool, handlebars at the sink and a seat in the shower stall.

Kitchen modifications - Modifications such as lowered countertops, special slip-resistant floors, and special levers or knobs on doors for persons with a disability or health problem.

Alerting devices - Devices used to inform sensory impaired persons of phone calls, someone at the door, or a fire. This does not include standard doorbells or smoke alarms.

### C. Instructions

1. For question 1a in multi-unit structures, include stairs or steps inside the building used to gain access to the unit as well as stairs or steps from the outside into the building. If the stairs or steps can be avoided by using another entrance or elevator, mark "No."
2. Mark "No" in question 1a without asking if you gained access to the unit without going up or down a step. However, if you used a step(s), you must ask the question because the presence of other entrances which may not have a step (level access, ramp, elevator) is not always obvious.
3. Mark "Yes" in 1b without asking if the unit is obviously multi-level, including split foyers and split levels, as well as units with basements or stepdown living areas. However, do not assume that trailers, ranch or rambler style houses are single level and mark "No" without asking, because the presence of basements or stepdown living areas is not always obvious. The procedure is the same for apartments. If you can see various levels in the apartment, mark "Yes" in 1b without asking; otherwise, be sure to ask. Don't assume apartments are all on one level. Also, many apartment buildings have storage areas or common areas such as a lounge or recreation room. Do not consider these to be part of an apartment.
4. For question 1c, the rooms do not have to be used by the sample person in order for "Yes" to be marked. Remember that these questions are asking about the physical characteristics of the living quarters and not necessarily only those parts of the living quarters which the child uses.

5. The difficulty referred to in question 2 must be caused by physical impairment or health problem and not because the child is too young. If a respondent reports that a child has difficulty using the bathroom only because he is not yet potty-trained, mark "No" in question 2d.
6. Mark "Yes" in question 4 for any special feature that the child needs, whether or not it is present in the home.
7. If the respondent asks what is meant by special equipment on a motor vehicle, read the 6b answer categories as examples.
8. The special equipment in question 6 must be on the motor vehicle or needed on the motor vehicle because of an impairment or health problem the child has. For example, it is unlikely that a car is equipped (or needs to be equipped) with hand controls, automatic transmission, etc. because of a health problem of a very young child. However, these may be required for a 16 or 17 year old to drive the vehicle. Ask the questions regardless of the child's age, but emphasize the concepts of being present or needed only because of the child's health or physical impairment.

## SECTION M. HEALTH INSURANCE

### A. Objective

The information collected in Section M will help assess the use and/or need for health insurance by children and their families.

### B. Definitions

Medicaid - A medical assistance program that provides health care to low income and disabled persons. The Medicaid program is a joint federal - state program which is administered by the states and may have a state assigned name.

VA - Refer to page 7-4.

CHAMPUS - Refer to page 7-4.

CHAMPVA - Refer to page 7-4.

Private Health Insurance Plan - Any type of health insurance (other than the public programs in questions 1-4), including coverage by a health maintenance organization (HMO) AND single service plans.

Health Maintenance Organization - Refer to page 7-24.

### C. Instructions

1. Refer to page 10 of your DFS-10 Information Booklet for alternate state names for Medicaid when asking question 1. If the state in which you interview uses an alternate name which is not on this card, write it on the card for your benefit and notify your supervisor so that the card may be changed in a later printing.
2. "(Month)" refers to the month prior to the one in which the interview is being conducted. For example, when interviewing in November, insert "October" in these questions.
3. If the response to 1b is an answer category cut-off point (e.g., 6 months, 1 year, 2 years, etc.), probe by asking: "Would you say that was a little more than \_\_\_\_\_ or a little less than \_\_\_\_\_?" Then mark the appropriate category based on the response to this probe.
4. If it is volunteered that the child was eligible for VA or military health care, even if not used last month, mark "Yes" in 3a.
5. Include the parenthetical in 5a if "yes" was marked for any programs in questions 1-4.

6. Question 5b concerns how the insurance was originally obtained, not necessarily how it currently is carried.
7. If the answer to 5b is "yes", probe to determine if it was obtained through an employer or union.

## SECTION N. RESPONDENT INFORMATION

### A. Objective

The objective of this section is to clarify the relationship between the respondent and the sample child. This will assist in the analysis of the data.

### B. Instructions

"Started living with you" refers to adopted, step and foster children. It is the point at which the child was adopted, when the respondent married into the child's family or when the respondent assumed custody of the child as a foster parent.

## CONTACT PERSON INFORMATION

### A. Objective

The contact information collected here will enable the NCHS or Census to make further contact with this sample child should it be required.

### B. Instructions

Mark Check Item N1 based on the information printed on the cover label. If there is already a contact person listed on the label, ask 2a to verify that the information on the label is currently correct.

If there is no contact person on the label, ask question 2c to identify a contact person. Fill question 3 completely and legibly with the information the respondent gives you.

## **CHAPTER 8. DFS-2 ADULT'S QUESTIONNAIRE**

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### **BACKGROUND**

Disability and its impact on the well-being of the U.S. population has long been recognized as a major health issue. The treatment and prevention of disabling conditions have been important goals in the medical and social arenas. Ongoing prevention efforts require continued understanding of the nature of disability and its impact on the individual, family, and economy.

The DFS-2 Adult Questionnaire will be administered to disabled adults 18 years of age or older. These persons were identified as disabled in an earlier Health Interview Survey interview; thus, it is possible that some persons may no longer have the disabling condition. This, however, would be the exception rather than the rule.

### **INITIAL SCREENING QUESTIONS**

The initial screening questions will determine who, when, and where the interview will be conducted. Always assume you will interview the Sample Person until you are told otherwise by the respondent. If the "Sample Person" is not available or is incapable of being interviewed, conduct the interview with a proxy respondent.

### **Instructions**

1. Make arrangements for a callback and footnote the arrangements in the Notes space if the Sample Person will return to the area before closeout.
2. If the Sample Person has moved to a new residence, attempt to obtain the address and telephone number where he/she can be found. Record this information in the "new address" space on page 3.
3. If the Sample Person is temporarily absent and will not return before closeout, ask for collect the address and telephone number where he/she can be found. Record this information in the "new address" space on page 3.
4. If the Sample Person is cannot be interviewed, identify a proxy, respondent who knows about the Sample Person's health to conduct the interview with.
5. If the Sample Person has died, record the date of death in question 6, the place the Sample Person died in question 7 and end the interview. Mark Box 07 - Deceased in the noninterview section on the cover page.
6. Sample Persons currently in a hospital, nursing home, convalescent home, hospice, and the like are considered to be "institutionalized" for the purpose of the DFS-2 interview. Ask your respondent if it is possible to interview the Sample Person at the institution (question 4d). If so, follow the guidelines in Chapter 12 for conducting interviews in institutions. Regardless of whether you interview the Sample Person in an institution or a proxy respondent for an



institutionalized Sample Person, some questions in the DFS-2 simply don't apply. Fill the check items and/or follow the skip instructions for institutionalized Sample Persons.

7. Begin the interview with Item A located near the bottom of page 2. The Sample Person may have had a birthday since the HIS interview, or the age may have been keyed or recorded incorrectly. Therefore, always verify the Sample Person's age and make corrections, if necessary, right on the label.

## SECTION A. HOUSING AND LONG-TERM CARE SERVICE

This section obtains information about the Sample Person's residence. Information about the physical characteristics of the residence and special services which may be available at this residence are important in determining what aspects of the Sample Person's environment allow him or her to remain independent and to continue living in the community.

These questions ask for some detail regarding the structural characteristics of the Sample Person's living quarters. When combined with other information, they will help identify housing features which may make it difficult for the Sample Person to continue living in his or her own home.

### QUESTIONS 1-5

These questions determine whether the Sample Person experiences any difficulty in the residence where he/she lives, or if the residence contains any special features to improve access.

#### A. Definitions

Bathroom modifications - Includes modifications that would help the individual, for example, a raised toilet seat, grab bars near the toilet, tub stool, grab bars in tub, handle bars at sink, and seat in shower stall.

Kitchen modifications - Includes modifications such as lowered counters, special slip resistant floors, and special levers or knobs on doors for persons with a disability or health problem.

Alerting devices - Devices used to inform sensory impaired persons of phone calls, someone at the door, or fire. This does not include standard doorbells or smoke alarms.

#### B. Instructions

1. If the person has lived in the same building but in different apartments, consider the one he or she is currently living in only. For mobile homes, question 1 refers to the present site or location. If the person has more than one residence, record the number of years the person has lived at this residence.
2. Record the answer verbatim, including fractions, or mark the "less than 1 year" box.
3. For multi-unit structures, include stairs or steps inside the building used to gain access to the unit as well as stairs or steps from the outside into the building. If it is reported that the stairs or steps can be avoided by using another entrance or elevator, mark "No."
4. Mark "No" without asking if you gained access to the unit without going up or down a step. However, if you used a step(s), you must ask the question because the presence of other entrances which may not have a step (level access, ramp, elevator) is not always obvious.

5. Mark "Yes" in 2b without asking if the unit is obviously multi-level, including split foyers and split levels. However, do not assume that trailers, ranch or rambler style houses are single level and mark "No" without asking, because the presence of basements or stepdown living areas is not always obvious.
6. The procedure is the same for apartments. If you can see various levels in the apartment, mark "Yes" in 2b without asking; otherwise, be sure to ask. Don't assume apartments are all on one level. Also, many apartment buildings have storage areas or common areas such as a lounge or recreation room. Do not consider these to be part of an apartment.
7. For question 2c, the rooms do not have to be used by the Sample Person in order to mark "Yes". These questions are asking about the physical characteristics of the living quarters and not necessarily only those parts of the living quarters which the Sample Person uses.

## QUESTIONS 6-7

### A. Definitions

An Assisted Living Facility - A facility which contains private occupancy units with full bathrooms, lockable doors, and possibly kitchenettes with cooking capacity and which provides at least some of the following services: personal care, supervision and oversight, nursing for other home health, and coordination or arranging of services for persons with mental or physical limitations.

Center for independent living - A residential facility that provides training to persons with disabilities to learn to live independently.

Developmental center - A residential institution for persons with mental retardation. It is not a nursing home.

Group home - A residential housing several people with disabilities that usually has a person without disabilities who also resides there to provide assistance.

Halfway house - A transitional dwelling center for people to learn how to live in the community after being released from a prison, mental or substance abuse facility or other residential treatment center.

Nursing or convalescent home - Those facilities that are used following surgery, chronic illness, or severe injuries to allow patients to recuperate with less medical care than found in a hospital. Convalescent homes provide personal care but not necessarily nursing care.

Personal care or board and care home - A home in which meals and assistance with eating, bathing, dressing, and toileting are provided.

Retirement home - Provides varied levels of care for older persons, and is not part of a large development.

Some other type of supervised group residence or facility - A catchall category for residential facilities that provide some level of supervision or oversight.

Supervised apartment - Individual apartments that provides a low level of oversight for residents who have some cognitive or physical disabilities.

**B. Instruction**

1. If the Sample Person is hospitalized at the time of the interview, mark Box 14 "Something else" in question 7a.

**QUESTIONS 8-10**

**A. Definition**

Protective oversight - Usually provided for persons with cognitive disabilities to ensure that they do not harm themselves or others. It is not for punishment (as in a prison) or a security (from trespassers).

Nursing or medical care - Care provided on the premises by trained medical professionals, including doctors, nurses, or medical technicians.

**B. Instructions**

1. The service does not have to be used by the Sample Person to mark "Yes" in question 8 (and 9). Also, the service does not have to be contained within the same building as long as it is the same community or complex.
2. If the continuity of question 9 is broken by a respondent explaining an answer, or otherwise not answering "Yes", "No", or "DK", repeat the lead-in with the next service. Otherwise, repeat the lead-in only if necessary, to emphasize the concepts of this question. We are not interested in services from outside of the residence. For example, do not mark "Yes" for j if the respondent says all help with laundry must come from the resident's families.

**QUESTION 11-12**

**A. Definitions**

Nursing Home - A place which provides nursing and/or personal care services (such as help with eating, dressing, bathing, walking, etc.) in addition to room and board. Nursing care may include services such as providing injections, catheterization, bowel/bladder re-training, and blood pressure, temperature, pulse, and respiration checks.

Time Stayed In A Nursing Home - This refers to separate stays in nursing homes, not the number of nights in the nursing home. If the Sample Person was moved (transferred) from one nursing home to another, include each as a separate stay, even if it was not overnight.

## **B. Instructions**

1. If the respondent volunteers the name of the institution in 11a and it includes the term "convalescent" "rest home," "sanitarium," or anything other than nursing, etc., reask the question emphasizing, "Nursing Home". Do not probe for this but, use the definition of a nursing home provided in A-1 above if asked what you mean by a nursing home.
2. In 11b, do not include short term furloughs as separate stays unless the person was officially discharged and later readmitted. For example, if the person stayed in a nursing home except for a weekend visit with relatives once a month, do not include these as separate stays, unless the person was discharged and readmitted each month.
3. Ask question 11c for the date of the first or only admission and questions 11d and 11e about the most recent stay if the person had more than one stay.
  - a. If there is only one stay reported in 11b, omit the parenthetical phrase when asking 11c and d. Otherwise, insert the phrase "the first time" in c and "the last time" in d.
  - b. In 11e, record the number of months, including fractions, or mark the "less than 1 month" box. If the respondent answers in days, weeks, or years instead of months, reask the question substituting "How many months" for "How long". If the respondent still reports another period, make no entry on the months line, but footnote the response.
  - c. In 11f, enter the number of weeks, in the past 12 months, including fractions, or mark the "less than 1 week" box. If the respondent answers in days, months, or years instead of weeks, reask the question substituting "How many weeks" for "How long". If the respondent still reports another period, make no entry on the weeks line, but footnote the response.
  - d. Do not attempt to reconcile any seemingly inconsistent answers between 11e and 11f that you notice during the interview. It is too difficult to determine truly inconsistent responses since a number of stays, admission dates, discharge dates, etc., also have to be considered.

## **QUESTIONS 13-15**

### **A. Definitions**

A Convalescent Home - See definition on page 8-4.

A Facility or Group Home for Persons With Mental Illness - A facility whose primary function is to serve residents with mental illness.

A Board and Care Home - A term used to describe a residential setting that provides either routine general protective oversight or assistance with activities necessary for independent living for mentally or physically limited persons, in addition to room and board.

A Facility for Persons With Mental Retardation - A facility whose primary function is to serve residents with mental retardation.

An Assisted Living Facility - See definition on page 8-4.

Any Other Long-Term Care Facility - Facility with an average length of stay exceeding 30 days which serves persons with either mental or physical limitations and cannot be classified into one of the aforementioned categories.

Publicly Funded Home Care - Provides services such as personal care, housekeeping, meals, nursing, or therapy that is either:

- Paid for by a public program like Medicare or Medicaid, or
- Provided at no charge or for a nominal fee by a public agency such as a local health agency, or
- Provided at no charge or for a nominal fee by a private organization supported by government funds

Community-Based Care - Services such as adult day care, group meals, therapy of counseling provided outside an individual's home needed because of mental or physical limitations.

## **B. Instructions**

1. Question 12a-c includes the current nursing home stay if the Sample Person is currently in a nursing home.
2. Mark in question 12a all sources of payment for the nursing home stay(s) in the past year.
3. If only one source of payment box is marked in 12a, transcribe that number to 12b without asking. Ask 12b only if more than one payment source is marked in 12a.
4. Ask 12c only if Box 01 "Self or family in household" is marked in 12. Include all payments that the Sample Person or his/her family were billed for in the past 12 months.
5. Ask question 13 for each facility before asking question 14a.
6. Ask question 14a-e only for "Yes" responses to 13. This question refers to current stay if the respondent is now in the facility or the most recent stay if they are not currently in the facility.
7. Ask 15a even if the respondent currently lives in one of these facilities. They may be on a waiting list for a different facility of the same type.

## SECTION B. TRANSPORTATION

### A. Definitions

Special equipment--Equipment added to a car by the factory or after the purchase, that is needed to overcome an impairment.

Other special features--This would include special or specific placement of necessary controls or easy to handle controls.

Transit authority--Regional or local government or private organizations that operates the regular public transportation system.

Government program--Include transportation funded by state, county, and local government. For example, school buses for special education programs or shuttles for persons in vocational rehabilitation programs.

Other private source--A service provided by a private nonprofit organization (which may get some public funding); for example, a bus provided by an adult day care center to take people shopping.

Some other rail system--Public transportation run on rails, excluding subways and long distance train systems. Included are raised rail or elevated rail systems ("el") and commuter trains.

Difficulty--Respondent-defined.

Accessible bus--Bus that has special accommodations for entering and leaving by persons with disabilities. Especially for those in wheelchairs.

Ferryboat--A boat used to transport passengers, vehicles or goods.

Getting around outside home--Respondent-defined.

Limit of prevent use--Respondent-defined.

Past week--Past 7 days.

Cognitive/mental problems--Include psychiatric disabilities or learning problems that make using public transportation systems difficult or impossible.

Mobility training--Training for persons with cognitive or emotional impairments who can be educated to use the public system.

## **B. Instructions**

1. "Old age", "near blind", and the like are considered as impairments or health problems for questions 2, 3, 6b, and 6d.
2. Read only the bold answer categories when asking question 7.
3. Do not include "riding in a taxi cab", as a response for question 10b-"Ride as a passenger in a car."
4. Calculate the number of times a person flew on a plane for question 11a as follows:
  - If a person takes a nonstop flight, that counts as one time.
  - If a flight stops one or more times but the person stays on the same plane, count that as one time.
  - If the plane stops and the person changes planes one or more times to get to their destination, count the number of different planes they were on for that trip.
5. Add up the answer to 11a. Make an attempt to reconcile responses that do not add up, if necessary. If the respondent doesn't know the size of the plane, mark the DK box in 11b-e or 11f.
6. Read the bold answer categories as part of question 11f.
7. Include long distance private tour buses in question 12a.
8. Exclude short or commuter rides in question 12b.
9. Include ships/boats that sail a few hours or days that return to the same harbor without docking elsewhere in question 12c.



## SECTION C. SOCIAL ACTIVITY

This section includes questions about various activities the Sample Person may have participated in.

### QUESTIONS 1 - 4

#### A. Definitions

Past 2 Weeks - The 14 days immediately preceding the day of interview.

Get Together With - This excludes chance meetings, such as at church, a store or across the backyard fence, which do not go beyond a greeting made in passing. The word "socially" is meant to convey a planned encounter.

Friends/Relatives/Neighbors - These terms are respondent-defined.

Social Activities - Respondent-defined.

#### B. Instructions

1. Repeat the reference period as needed when asking 1b-g to be sure the respondent understands the reference period.
2. It is possible that some of the activities may overlap, for example, if the person went to a church club social activity, the answer could be "Yes" in 1a, c, e, and f. Accept whatever the respondent reports.
3. Do not include "relatives" as "friends or neighbors" in 1a and b. If the Sample Person lives alone, do not read the phrase, "not including these living with you" in 1c and 1d.
4. Ask 2 for each activity marked "Yes" in 1.
5. For question 3, include trips away from the property completely; not going outside into the yard or courtyard. However, provide this explanation only if asked; otherwise, accept the respondent's answer without question so long as it refers to the number of days not the number of trips. (The largest number you can record in question 3 is 14, the total number of days in a 2-week period.)
6. Ask question 4 of Sample Persons only (not proxy respondents) to determine their opinion of their present level of social activities. If necessary, explain to assistants that only the Sample Person should answer this question. If the Sample Person cannot or will not answer, mark "DK" or enter "REF" as appropriate. Do not record the opinion of the person assisting the Sample Person.

## SECTION D. WORK HISTORY/EMPLOYMENT

### A. Objective

The questions in this section focus on how ongoing health problems, impairments, or disability limit the Sample Person's ability to work.

### B. Definitions

Working For Pay - Includes working at a job for wages, salary, commission, piece rate, or pay-in-kind, such as receiving room and board for work performed.

Working For Profit - Includes working in your own unincorporated business or farm, as well as doing unpaid work in a family business or farm.

Looked For Work - Means actively looking for work or making an effort to get a job or establish a business.

Volunteer Work - Provide a service willingly and without pay for any organized group. This includes such activities as collecting for the March of Dimes, overseeing playground activities, working as a hospital volunteer, at church, etc. Do not include such events as voluntarily going to the store for a neighbor, babysitting, etc., if it was not through an organized group.

Limit Ability to Work - Can only partially perform activities, can fully perform work activities only part of the time, or cannot work at all.

SSI - Supplemental Security Income - A Social Security Administration program that makes assistance payments to low income, aged, blind, and disabled persons. Some states may have their own SSI program.

NOW - Means current employment, even if Sample Person is on vacation.

Elevator For Special Need - May have recorded voice announcements, braille, or lowered instrument panels.

Work Station - Can be a room for a wheelchair, special lighting, special communication equipment and the like.

Job Coach - Is usually used by people with cognitive or psychiatric impairments to teach job skills, remind a person how to do tasks, and oversee their work.

Personal Assistant - One who provides functional duties like reaching, carrying, and writing, as well as assisting with personal care (eating, toileting) during work hours.

### C. Instructions

1. Depending on each Sample Person's situation, variations of the same sets of questions are asked. To avoid asking the same question more than once or asking an appropriate questions, follow the skip instructions carefully when completing Section D.
2. For questions 4, 10, 12, 13b, 19, 22a, 26a, 28, 31a, 33a, 36a, 41, 42, 43b, 45, 51, 65, 67, 68b, 70, 77, 79, 80b, 82, 85, and 90, repeat the lead-in whenever there is a break in the continuity of the questions (such as when the respondent explains an answer instead of giving a Yes or No response) and any time you feel it is necessary to remind the respondent of the basic question.
3. For questions 7, 15, 26c, 36c, 47, 53, 56, 60, 72, 84, and 92, record the response as reported and do no attempt to convert it to a different time period unless it is not given as days per week, month, or year. For example, enter "365 days per year" if that is what is reported; however, for a response such as "2 days every quarter", verify and record "8 days per year"; or "one day every other week", verify and record "2 days per month" or "26 days per year".
4. For questions 22, 23, 31 and 33, ask first about the "need" for each special feature, equipment, or work arrangement. Then, for each "Yes", ask about the presence at work.

## SECTION E. VOCATIONAL REHABILITATION

### A. Objective

This section contains questions about vocational rehabilitation services. These services are designed to help people find a job, get back to work, or simply function better in their everyday activities.

### B. Definitions

Vocational Rehabilitation Services - Vocational Rehabilitation is a process of restoring persons with disabilities to the highest level of economic functioning of which they are capable. The process involves the delivery of a wide variety of goods and services needed by such individuals to make them employable.

On-The-Job Training - This is training by a prospective employer in which the client usually works for wages while learning the skills of a job.

Training In Job Seeking Skills - This is training designed to help the individual find a job. It involves instruction on how to read want ads and other sources of job information, preparing a job resumes and cover letters, and preparing for job interviews.

Vocational Or Business School Training - Included is training in (a) a business/commercial school or college and (b) a vocational/trade school. Training in the business/commercial school or college would prepare the individual for work in areas of office practice, typing, data processing, etc. Training in vocational/trade school would generally prepare the individual for occupations such as welding, TV repair, cosmetology, etc.

College Or University Training - Included is all academic training on a level higher than a secondary education. Individuals attending full- or part-time or evening courses conducted by a university, college, junior college, or a college-level extension school should be included.

Personal Adjustment Training - This is training which helps the individual adjust to a particular situation hindering his or her ability to work. Included would be work conditioning; developing work tolerance; training in the use of artificial limbs, aids, or appliances; mobility training; remedial training; literacy training; braille; etc.

Physical Therapy - Refers to therapy to develop, improve, or restore gross motor movements, such as walking.

Occupational Therapy - Refers to therapy to develop, improve, or restore fine motor skills, usually involving the use of the fingers, hands, and arms.

Other Medical Treatment - This includes surgery, hospitalization, medical consultations and other treatments undertaken as part of a program of vocational rehabilitation.

Training In Homemaking - This is training designed to help an individual function more effectively in his or her own home. It could include assistance in activities such as preparing meals, making beds, washing laundry, sewing, etc.

Training In Self-Care - These services help the individual to maintain or improve daily functioning whether inside or outside of the home. They can range from showering and dressing at home to shopping and getting around outside of the home.

Sheltered Workshop - This is a work setting operated by non-profit organizations for persons with severe disabilities who are unable to enter or are not ready for competitive employment.

Supported Employment - These are services designed to help persons with severe disabilities find a job in competitive employment in integrated work settings. The individuals are so severely disabled that after placement they will typically need ongoing support services to help them retain the job, such as the assistance of a job coach.

Driver Training - Driving instructions for persons with limited use of their arms and/or legs, including how to use adaptive driving technology.

Other Rehabilitation Services - Included would be services such as reader or interpreter services, occupational tools and equipment and services to family members for the benefit of the individual.

### C. Instructions

1. Ask all of question 1a (1)-(15) before going to 1b. Then ask 1b only for the services marked "Yes" in 1a.
2. Include the parenthetical in question 4 if any of the services are marked "Yes" in 1a. Do not read the parenthetical if no "Yes" boxes are marked in 1a.
3. Ask all of question 5a (1)-(11) to identify the Sample Person's current employment and other activities. "Current" is respondent-defined, but is not limited to the time or day of the interview. For example, mark "Yes" in 5a (9) if the Sample Person "currently" is on a break or vacation from school, but intends to return following this break/vacation.
  - a. Ask 5a (12) only if 5a (1)-(11) are all "No". 5a (12) may easily be misinterpreted: If the Sample Person participates in no structured activity at all, mark "Yes" in 5a (12); if the Sample Person participates in some structured activity other than those named in 5a (1)-(11), mark "No" in 5a(12).
  - b. The skip instruction above 5a (12) is incorrect. It should read: "Ask if all "No" in 5a (1)-(11); otherwise, go to 5b."
  - c. Ask 5b for each activity marked "Yes" in 5a (except 5b (12)).

**SECTION F. ASSISTIVE DEVICES AND TECHNOLOGY**

Refer to Section D pages *7-10* and *7-11* for definitions and instructions.

## SECTION G. HEALTH INSURANCE

### A. Objective

The information collected in Section G will help assess the use and/or need for health insurance by the Sample Person. *Refer to Section M, page 7-27 for definitions and instructions.*

### B. Definition

Medicare - Refers to the Federal health insurance coverage most common for persons 65 years and over. In certain situations people under 65 may be covered.

## SECTION H. ASSISTANCE WITH KEY ACTIVITIES

### Objective

Section H determines the degree of difficulty the Sample Person has in performing a variety of activities, including basic activities of daily living (ADL's) and instrumental activities of daily living (IADL's). Many of these activities have been found to be valuable indicators of health and the potential need for future care, either at home or in an institution.

### General Instruction

The time frame for most of the questions in Section H is "current", that is, around the time of the interview.

### QUESTIONS 1 - 3 ACTIVITY LIMITATIONS

#### A. Definitions

Aids - Equipment or devices used to assist the person in a particular activity, such as a cane or walker, artificial limb, etc. Also include as aids special shoes, chairs, structural modifications to the home, such as railings on stairs or walls, and other things used for performing the activities only if they are of special construction, design, etc., or were installed to specifically assist the Sample Person in accomplishing an activity.

Difficulty - Respondent-defined.

#### B. Instructions

1. Read the introduction, ask all of questions 1a through j consecutively and mark the appropriate box for each. Then ask 2 and 3 for each "Yes" answer marked in 1.
  - a. Repeat the leadin, "By yourself and not using aids, do you have any difficulty \_\_\_" anytime there is a break in the continuity of the questions to remind the respondent of the qualifications in the original question. For example, if the respondent explains his/her answer to 1b instead of answering with a "Yes" or "No", repeat the leadin when asking 1c.
  - b. If the Sample Person never does the activity, probe to determine if he/she is unable to do it. If so, mark the "Yes" box. (You may verify "unable to do it" instead of asking question 2.) If the person never does the activity for some other reason and thus can't judge whether he/she has any difficulty, mark box 9, "NA/DK."



2. After completing all of question 1, ask question 2 inserting the appropriate activity for which a "Yes" response was received. You may omit the phrases in parentheses when asking questions 2 and 3.
3. Ask question 3 for that activity immediately after asking question 2. The wording of the activity will have to be modified when reading question 3 for "unable". For example, "... been unable to walk for a quarter of a mile ...".

#### QUESTION 4 DIFFICULTY WITH ADLS

##### A. Definitions

Special Equipment - Mechanical aids or devices used to assist the person in a particular activity, such as a cane, walker, artificial limb, guide dog, special plates, etc. Also, include structural modifications to the home, such as lowered or raised commodes, lowered or raised kitchen equipment, ramps, etc.

Getting Outside - Moving from inside the unit to outside, including to a patio, porch, or a building hallway. It does not imply any real movement or exertion once the person has reached the outside.

Bed - Anything used for lying down or sleeping, including a sofa, cot, or mattress.

Difficulty - Respondent-defined.

##### B. Instructions

1. Read the introductory statement ask question 4 for all activities A through G and determine if the SP has any difficulty with each. If necessary, remind the respondent that the questions should be answered based on "by yourself and without using special equipment." Reread question 4 before you ask (D), "getting in and out of bed or chairs?" and at any other time you feel it necessary to remind the respondent we are referring to difficulty because of health or physical problems.
2. If the Sample Person doesn't do the activity, ask the "doesn't do" probe to determine if this is because of a health or physical problem. Mark box 3 if the activity is not performed because of some other reason. For example; if the response to the "doesn't do" probe is:
  - "Yes, my arthritis is so bad that my daughter has to bathe me." Mark box 1.
  - "I never go outside, this area is too dangerous." Mark box 3.

**CHECK ITEM H1 AND QUESTIONS 5 - 6  
DEGREE OF DIFFICULTY WITH ADLS**

For those reporting any difficulty in 4, ask how much difficulty the SP has doing that activity in question 5 and what types of difficulty he/she experiences when doing the activity alone and without using special equipment in question 6. Questions 5 and 6 will not be asked if the SP indicates in question 4 that he/she has no difficulty with the specific activity.

**A. Definitions**

Tiring - Respondent-defined.

A long time - Respondent-defined.

Painful - Respondent-defined.

**B. Instructions**

1. Refer to question 4 to mark Check Item H1. If the SP had difficulty with an activity ("Yes" in 4), mark Box 1 "yes" in Check Item H1 for that activity and to ask questions 5 and 6 about the activity. If boxes 2, 3 or 9 are marked in question 4, mark Box 2 "all other" in Check Item H1 for the activity and skip to Check Item H1 for the next activity.
2. Insert the appropriate activity (ADL) when asking questions 5 and 6.
3. If in response to 6 (1) you are told that the Sample Person never does the activity without help or special equipment, mark box 0 at the top of the answer space and skip to H1 for the next activity. Do not complete 6 (1), (2) and (3) in this situation.

**CHECK ITEM H2 AND QUESTION 7a - c  
SPECIAL EQUIPMENT WITH ADLS**

Questions 7 a through c ask about the use of special equipment or aids while doing the activities (ADL). Even if "no difficulty" was reported in 4, the Sample Person may still use special equipment.

**A. Definition**

Special Equipment - See definition on page 8-9.

Tiring/Long time/painful - Respondent-defined.

**B. Instructions**

1. Refer to question 4 to fill Check Item H2. If the SP doesn't do the activity, (box 3 in 4), mark Box 1 "Box 3 marked" in Check Item H2 for that activity and skip to Check Item H2 for the next activity. If Boxes 1, 2 or 9 are marked in question 4, for the activity mark Box 2 "All Other" in Check Item H2 and ask question 7a through c for the particular activity.

2. Insert the appropriate activity (ADL) when asking 7a and 7c.

**CHECK ITEM H3 AND QUESTIONS 8a - e  
HANDS-ON HELP WITH ADLS**

**A. Definition**

Another person - A friend relative, paid helper, volunteer from an agency or organization or anyone else who helps the Sample Person in doing the activity. He/shé may be a household member or a non-household member

Hands-on Help - Hands-on help is active physical help that involves touching the Sample Person, as opposed to supervision, standing nearby in case of difficulty, verbal cues, reminders or financial help. The table below gives examples of hands-on help for each ADL. (Hands on help is not limited to these examples however).

ADL	Hands-on Help	Not Hands-on Help
Bathing or Showering	<ul style="list-style-type: none"> <li>- Helping Sample Person in or out of tub or shower</li> <li>- Bathing Sample Person</li> </ul>	<ul style="list-style-type: none"> <li>- Turning on water</li> <li>- Washing hair only</li> <li>- Reminding SP to bathe</li> </ul>
Dressing	<ul style="list-style-type: none"> <li>- Putting clothes on/taking clothes off Sample Person</li> <li>- Fastening closures such as buttons, snaps, zippers, hooks</li> </ul>	<ul style="list-style-type: none"> <li>- Taking clothes out of closets or draws</li> <li>- Selecting cloths</li> <li>- Tying shoes only</li> </ul>
Eating	<ul style="list-style-type: none"> <li>- Feeding Sample Person</li> <li>- Helping Sample Person drink from a cup or glass</li> </ul>	<ul style="list-style-type: none"> <li>- Cutting meat, buttering bread</li> <li>- Serving or preparing food</li> </ul>
Getting in and out of bed or chair	<ul style="list-style-type: none"> <li>- Holding or supporting Sample Person while she/he got out of bed or chair</li> <li>- Lifting Sample Person out of bed or chair</li> <li>- Helping Sample Person use lifts, trapezes or other transfer equipment</li> </ul>	<ul style="list-style-type: none"> <li>- Staying nearby in case help is necessary</li> </ul>
Walking	<ul style="list-style-type: none"> <li>- Holding or supporting Sample Person</li> <li>- Assisting with the use of special equipment</li> </ul>	<ul style="list-style-type: none"> <li>- Walking along side in case help is needed</li> </ul>
Getting Outside	<ul style="list-style-type: none"> <li>- Holding or supporting Sample Person</li> <li>- Assisting with the use of special equipment</li> <li>- Helping Sample Person get up or down stairs</li> </ul>	<ul style="list-style-type: none"> <li>- Walking along side in case help is needed</li> </ul>
Using the Toilet	<ul style="list-style-type: none"> <li>- Help walking to or from the bathroom or commode</li> <li>- Help transferring on or off the toilet seat</li> <li>- Help with cleaning after elimination</li> <li>- Help adjusting clothes</li> <li>- Changing adult diapers</li> <li>- Help with a bedpan</li> <li>- Help with catheter or colostomy</li> </ul>	<ul style="list-style-type: none"> <li>- Reminders to use the toilet</li> <li>- Staying nearby in case help is needed</li> </ul>

Tiring/long time/painful - Respondent-defined.

**B. Instructions**

1. Refer to question 4 to fill Check Item H3 for each activity. If the SP doesn't do the activity (box 3 in 4) mark Box 1 "Box 3 marked" in Check Item H3 for that activity and skip to Check Item H3 for the next activity. If boxes 1, 2 or 9 are marked in question 4 for the activity mark Box 2 "All Other" in Check Item H3 and ask question 8a through e for the particular activity.
2. Mark "Yes" in 8a even if the respondent qualifies the answer with "sometimes", "under certain circumstances", or the like.
3. If in response to 8c (1), you are told the Sample Person never does the activity because the helper always does it for him/her, mark box 0 "Never does activity" and skip to question 8e. Do not complete 8c (1), (2), and (3) in this section
4. Question 8e measures unmet need for each ADL. Read "need more hands-on help" for SPs who indicated in 8b that they receive hands-on help. Read "need hands-on help" for those SPs who indicated they do not receive hands-on help.

**CHECK ITEM H4 AND QUESTIONS 9 - 11  
SUPERVISORY HELP WITH ADLS**

Questions 9 through 11 ask SPs who are not receiving hands-on help about receiving supervisory help while doing the activities asked about in 4. As before, Sample Persons who currently get help "sometimes" or "under certain circumstances" should be recorded as getting help.

**A. Definition**

Another person - See definition on page 8-20.

Supervisory Help - Inactive assistance such as verbal cues or reminders to the SP. Helpers often sequence events for SPs, for example, first sit up, now swing your feet to the side of the bed, hold onto the rail, put both feet on the floor, etc.

Standby Help - Inactive assistance such as standing by ready to provide hands-on help or verbal support if necessary.

**B. Instructions**

1. Refer to Check Item H3 and question 8b to fill Check Item H4 for each activity. If Box 1 is marked in H3, mark Box 1 in Item H4 and go to Item H4 for the next activity. If Box 1 "Yes" is marked in 8b mark Box 2 of Item H4 and go to Item H4 for the next activity. In all other situations, mark box 3 and ask questions 9 through 11 for that activity.
2. Mark "Yes" in 9a 6 (1), or 6 (2), if the respondent qualifies the answer with "sometimes", "under certain circumstances", or the like.

3. Question 11 measures unmet need for supervisory or standby help for each ADL. Read "need more supervision or standby help" for SPs who indicated they receive supervisory or standby help in 9a read "need supervision or standby help" for SPs who indicated in 9a that they do not receive supervisory or standby help.

**CHECK ITEM H5 AND QUESTIONS 12 AND 13  
NEGATIVE CONSEQUENCES FOR ADLS**

Questions 12 and 13 are asked ONLY if the SP reported receiving OR needing help or supervision from another person with the specific activity. Each activity has its own, unique set of questions, located in each column.

**A. Definitions**

Complete Bath - A complete bath is one where the Sample Person's full body, including the back and feet, is washed. A complete bath does not have to take place in a tub or shower. Sample Persons may bathe completely at a sink or basin or in bed.

Partial Bath - A partial bath is a bath in which only part of the Sample Person's body is washed.

As often as you would have liked - Respondent-defined.

Discomfort - Discomfort may be either physical or emotional, but is respondent-defined.

All or most of the time - Less often than once a day.

Scald or Burn - A scald is a burn caused by hot liquid or steam.

Dress for the day - Putting on clothing other than that normally worn for sleeping. "Day" refers to the time the person usually is awake.

Night cloths - Sleeping apparel regardless of when they are worn.

Hungry - Respondent-defined.

Dehydration - Dehydration is a condition in which a person's water content has fallen to a dangerously low level. Dehydration may occur because water intake is not sufficient or as a result of vomiting or diarrhea. Symptoms and signs of dehydration include severe thirst, dry lips and tongue, an increase in heart rate and breathing, dizziness and confusion. The skin will look dry and lose elasticity.

Bed - See definition on page 8-18.

Rash - A skin irritation that results from prolonged exposure to substances contained in feces or urine; or irritation from rough, wet, or soiled fabrics.

Commode - A portable toilet, a chair enclosing a chamber pot.

## **B. Instructions**

1. Refer to questions 8a, 8e, 9a, and 11, to fill Check Item H5 for each activity. If Box 1 "Yes" is marked for at least one of these questions, to mark Box 1 in H5 and ask questions 12 and 13 as appropriate for the particular activity. If "Yes" is not marked for all four questions, skip to Check Item H5 for the next activity.
2. If the response to 12a or 12b (activity A), 12b (activity B) or 12c (activity D) is "NEVER", mark box 4 "Less than once a week."
3. In question 12a-B (activity B), mark "4 - STAY IN NIGHT CLOTHES" if the Sample Person, changes pajamas or nightgowns every day but never get dressed in "street clothes".
4. Question 12a (activity C) refers to help eating, not help with meal preparation.
5. Question 12b (activity C) refers to weight loss due to dieting in (1) while question 12c (2) refers to weight loss even though the SP was not dieting. Mark "Yes" for the appropriate item if there was any amount of weight loss in the past month.
6. In question 12c (Activity D), indicate the weekly frequency with which the Sample Person gets out of bed for any reason, even if it is just to use the toilet, open or close windows, or some other mundane reason.
7. For question 12a (Activity E) read the categories slowly but do not pause after each for an answer. Stop, however, if the Sample Person gives an answer before you complete reading all categories.
8. Questions 12a (Activity G) about toileting may be embarrassing for some respondents. Ask these questions in a pleasant but business-like manner, always maintaining neutrality.
9. When asking questions 12a-c for Activity G, emphasize, "because you did not have help" and "because no help was available."

### **CHECK ITEM H6 AND QUESTIONS 14 AND 15 CONDITION(S) CAUSING TROUBLE WITH ADLS**

Questions 14 and 15 are asked of Sample Persons who reported having any difficulty with one or more of the activities to ascertain the medical conditions that cause the difficulty and whether the condition(s) were the result of an automobile accident.

## **A. Definitions**

Old Age - Consider responses such as "getting old," "too old," etc., to be the same as "Old age". Do NOT, however, consider conditions which are often associated with old age; such as "senile," "senility," "muscular degeneration," etc., to be the same as "Old age." If in doubt, treat the response as a condition rather than old age.

Motor Vehicle Accident - an event causing loss or injury involving a self-propelled, power operated vehicle, not on rails and intended for use on a highway. This includes non-highway vehicles, such as construction equipment or farm machinery, when operated on a highway. The motor vehicle does not have to be moving or on a highway at the time of the accident. Likewise, the Sample Person does not have to be "in" the vehicle at the time of the accident.

## **B. Instructions**

1. Refers to question 4 A-G and mark each activity in Check Item HG for which the SP had any difficulty (i.e., Box 1 "yes" is marked in 4). If the SP didn't have difficulty performing any of the activities, mark the bottom box in H6 "No activities marked" and skip to question 16. Otherwise, continue with question 14a, inserting all of the activities marked in Item H6 when asking this question.
2. If multiple activities are involved, use the word "and." For example, "What condition causes the trouble in dressing, walking, and getting outside?"
3. If the difficulty was the result of an operation, probe for the condition(s) which caused the operation. If you cannot determine a condition, enter the operation.
4. Ask or reask 14b each time a condition (other than old age) is reported in 14a. For each "Yes" response to 14b, reask 14a (including the parenthetical "other") and 14b until you receive a "No" to 14b.
5. Ask question 14c only if "Old age" is reported in 14a.
6. Record up to 5 conditions, in 14a. If the respondent says there are more than 5 conditions, record the 5 the respondent considers to be the "Main" causes of the difficulty.

## **QUESTION 16 TRAINING FOR INDEPENDENCE IN ADLS**

Question 16 is asked of everyone to determine whether the SP received training in life skills, such as the ADLs (bathing, dressing, eating, etc.).

### **Definition**

Training - Respondent-defined; although, an example would be training given to the SP to recover functioning after a stroke or trauma.

**QUESTIONS 17 - 18**  
**CONTROLLING BOWELS AND URINATION**

**Definitions**

Difficulty Controlling Bowels/Urination - Difficulty controlling bowels includes accidentally soiling one's self as well as chronic inability to empty the bowels, excluding occasional constipation. Difficulty controlling urination includes accidentally wetting one's self, including occasional slight "leaking."

Colostomy/Urinary Catheter/Other Devices - Surgical openings and/or devices used to aid in bowel movements or urination when the person has lost natural control of these functions through illness, disability, surgery, or other causes. Do NOT include enemas or suppositories as devices.

Help In Taking Care of This Device - Personal assistance or supervision is required and/or received in operating, maintaining or cleaning the device, emptying the bags, etc.

**QUESTION 19**  
**DIFFICULTY WITH IADLS**

The third set of activities refer to activities known as Instrumental Activities of Daily Living or IADL's. Because these activities are not relevant to persons in hospitals, nursing homes, and other institutions, SPs who are institutionalized at the time of the interview will skip all of the questions pertaining to IADLs.

The questions pertaining to the IADLs are almost identical to those for the ADLs. There is an additional question which asks, for those who do not do the activity whether someone else usually does it for them. Also, there are no questions about special equipment for the IADLs.

**A. Definitions**

Difficulty - Respondent-defined.

**B. Instructions**

1. Read the introductory statement and ask all of questions 19 H through O before going to Item H9. If necessary, remind the respondent that the questions should be answered based on "by yourself." Reread question 19 at any other time you feel it necessary to remind the respondent we are referring to difficulty because of health or physical problems.
2. If the response indicates the Sample Person doesn't do the activity at all, ask the "doesn't do" probe to determine if this is because of a health or physical problem. Mark box 3 if the activity is not performed because of some other reason. Then ask, "Does someone else regularly do this for you?"



**CHECK ITEM H9 AND QUESTIONS 20 AND 21  
DEGREE OF DIFFICULTY WITH IADLS**

**A. Definitions**

Tiring/A long time/Painful - Respondent-defined.

**B. Instructions**

1. Refers to question 19 to fill Check Item H9 for each activity. If the SP had any difficulty with the activity (Box 1 "Yes" in 19) mark Box 1 in Check Item H9 for that activity and ask questions 20 and 21 about the activity. If boxes 2, 3 or 9 are marked in question 19, mark Box 2 "All other" in Check Item H9 and skip to Check Item H9 for the next activity.
2. Insert the appropriate activity (IADL) when asking questions 20 and 21.
3. Activity I - shopping", does not include difficulty or needing help getting to or from the store, but only whether the person can shop without assistance while in the store itself. Activity N concerns getting to places outside of walking distance, including to shopping destinations.
4. Is in response to 21a you are told that the Sample Person never does the activity without help, mark Box 0 at the top of the answer space and skip to H9 for the next activity. Do not complete 21a-c in this situation.

**CHECK ITEM H10 AND QUESTIONS 22a - e  
HANDS-ON HELP WITH IADLS**

Question 22a through e ask about receiving help while doing the activities.

**B. Definition**

Hands-on Help - Hands-on help is active physical help that involves touching the Sample Person rather than supervision, standing nearby in case of difficulty, verbal cues, reminders or financial help.

**C. Instructions**

1. Refers to question 19 to fill Check Item H10 for each activity. If the SP doesn't do the activity mark Box 1 "Box 3 marked" in Check Item H10 for that activity and skip to Check Item H10 for the next activity. If boxes 1, 2 or 9 are marked in question 19 for the activity mark Box 2 "All Other" in Check Item H10 and ask question 22a through e.
2. Mark "Yes" in 22a even if the respondent qualifies the answer with "Sometimes", "Under certain circumstances", or the like.

3. If in response to 22c (1), you are told the Sample Person never does the activity because the helper always does it for him/her mark Box 0 "Never does activity" and skip to question 22e. Do not complete 22c (1), (2), and (3) in this situation.
4. Question 22e measures unmet need for each IADL. Read "need more hands-on help" for SPs who indicated in 22b that they receive hands-on help. Read "need hands-on help" for those SPs who indicated they do not receive hands-on help.

### **CHECK ITEM H11 AND QUESTIONS 23 - 25 SUPERVISORY HELP WITH IADLS**

Questions 23 through 25 ask SPs who do not receive hands-on help about receiving supervisory help while doing any of the activities asked about in 19. Sample Persons who currently get help "sometimes" or "under certain circumstances" should be recorded as getting help.

#### **B. Definition**

Another Person - See definition on page 8-20.

Supervisory Help - Inactive assistance such as verbal cues or reminders to the SP. Helpers often sequence events for SPs, for example, first take food out of the refrigerator, uncover the food, now put the food in the microwave and set the timer for 2 minutes, etc.

Standby Help - Inactive assistance such as standing by ready to provide hands-on help or verbal support if necessary.

#### **C. Instructions**

1. Refers to Check Item H10 and question 22b to fill Check Item H11 for each activity. If Box 1 is marked in H10, mark Box 1 in Item H11 and go to Item H11 for the next activity. If Box 1 "Yes" is marked in 22b mark Box 2 of Item H11 and go to Item H11 for the next activity. In all other situations, mark box 3 and ask question 23 for that activity.
2. Mark "Yes" in 23a, b, or c if the respondent qualifies the answer with "sometimes", "under certain circumstances", or the like.
3. Question 25 measures unmet need for supervisory or standby help for each IADL. Read "need more supervision or standby help" for SPs who indicated they receive supervisory or standby help in 23a. Read "need supervision or standby help" for SPs who indicated in 23a that they do not receive supervisory or standby help.

**CHECK ITEM H12 AND QUESTION 26  
NEGATIVE CONSEQUENCES FOR IADLS**

**A. Objective**

Question 26 is asked ONLY if the SP reported receiving OR needing help or supervision from another person with the specific activity. Each activity has its own, unique set of questions similar to the negative consequence questions located in each column.

**B. Definitions**

Discomfort - Discomfort may be either physical or emotional.

Hungry - Respondent-defined.

Special Diet - A special diet may be therapeutic such as a low sodium diet, a bland diet, a macrobiotic diet, or a diet that eliminates foods to which the Sample Person is allergic or sensitive. A special diet might also be a diet to meet certain religious or spiritual preferences such as a kosher diet or a vegetarian diet. It might also be a diet to help the Sample Person lose or gain weight.

Distress - Respondent-defined.

**C. Instructions**

1. Questions 26a-b (Activity H) refers to the preparation of food.
2. Ask question 26b (Activity H) for special diet preparation, and 26c (Activity H) **about foods that the Sample Person prefers and enjoys**.
3. Questions 26a-b for (Activity I) refers to being unable to follow a special diet or **missing a meal** because the SP was unable to shop for food.
4. When asking question 26c for Activity N, emphasize "unable to get to the store."

**CHECK ITEM H13 AND QUESTION 27  
FREQUENCY DOING IADLS**

For SPs who perform the IADLs either with or without difficulty, question 27 asks **how often they** personally perform the activity in their household.

**A. Instruction**

Check Item H13 indicates which activities the SP does not do. Skip over question 27 for those activities. In other words, do not ask the SP how often he/she does an activity if **he/she indicated** that he/she does not do the activity.

**CHECK ITEM H14 AND QUESTIONS 28 AND 29  
CONDITION(S) CAUSING TROUBLE WITH IADLS**

Questions 28 and 29 are asked of Sample Persons who reported having any difficulty with one or more of the activities to ascertain the medical conditions that have caused the SP to be physically impaired and whether the condition(s) were the result of a automobile accident.

**A. Definition**

Old Age - See definition on page 8-23.

Motor Vehicle Accident - See definition on page 8-24.

**Instructions**

1. Refer to question 19 H-O and mark each activity in Check Item H14 for which the SP had any difficulty (i.e., Box 1 "yes" is marked in 4). If the SP didn't have difficulty performing any of the activities, mark the bottom box in 14 "No activities marked" and skip to question 30. Otherwise, continue with question 28a, inserting all of the activities marked in Item H14 when asking this question.
2. If multiple activities are involved, use the word "and." For example, "What condition causes the trouble in shopping, managing your money, and doing heavy housework?"
3. If the difficulty was the result of an operation, probe for the condition(s) which caused the operation. If you cannot determine a condition, enter the operation.
4. Ask or reask 28b each time a condition (other than old age) is reported in 28a. For each "Yes" response to 28b, reask 28a (including the parenthetical " and 28b other") until you receive a "No" to 28b.
5. Ask question 28c only if "Old age" is reported in 28a.
6. Record up to 5 conditions in 28. If the respondent says there are more than 5 conditions, record the 5 the respondent considers to be the "main" causes of the difficulty.

**QUESTION 30  
TRAINING FOR INDEPENDENCE IN IADLS**

Question 30 is asked of everyone to determine whether the SP received training in life skills such as the IADLs (preparing meals, shopping, managing money, managing medication, etc.).

**Definition**

Training - Respondent-defined.

**QUESTIONS 31a-e  
FALLS AND DIZZINESS**

**A. Definition**

Dizzy/Dizziness - These terms are respondent-defined.

**B. Instructions**

1. Insert the interview date (e.g., October 15) when asking question 31a.
2. For question 31c, injuries from falls include but are not limited to fractures, bruises, cuts or scrapes, or loss of consciousness. Use the 31d answer categories as examples if you are asked what you mean by being injured.
3. In question 31d, mark all the injuries that the SP sustained from all of the falls he/she had in the past year. A loss of consciousness can both cause a fall and be the result of a fall. Be aware of this, but do not probe for this distinction. Other injuries from falls might include hypothermia (low body temperature), pneumonia if SPs lie on the floor for more than one hour, burns, and loss of blood. If any of these are reported, mark Box 4 in question 31d. It is not necessary to specify such "other injuries".
4. Mark "Yes" in 31e if at least one fall was the result of a lack of help. Likewise, mark "Yes" in 31f if at least one fall was due to the Sample Person's dizziness.

**CHECK ITEM H16 AND QUESTIONS 32 AND 33  
BEDSORES AND CONTRACTURES**

Questions 32 and 33 ask about bedsores/pressure sores and contractures.

**B. Definitions**

Past Three Months - Since the date of interview 3 months ago. For example, if an interview on October 15, the past 3 months are since July 15.

Bedsore - Bedsore or pressure sore are also known as decubitus ulcers. They are ulcers that develop on the skin of patients who are bedridden, unconscious, or immobile. They commonly affect victims of stroke or spinal cord injuries that result in a loss of sensation. Constantly wet skin caused by incontinence may also be a factor. Bedsore start as painful, red areas that become purple before the skin breaks down, developing into open sores. Once the skin is broken, bedsores become infected, enlarge, deepen, and are very slow to heal.

Contracture - Contractures are deformities caused by shrinkage of scar tissue in the skin or connective tissue or by irreversible shortening of muscles or tendons. Sample Persons may refer to contractures as joints that won't straighten out.

New Bedsores/contractures - Ones first occurring within the past 3 months as opposed to those starting more than 3 months ago, but lasting to within the past 3 months.

### **CHECK ITEM H17 AND QUESTIONS 34 AND 35 HELPER STRENGTH AND SP SAFETY**

Question 34 begins a series of questions designed to obtain characteristics about the person(s) who helps the SP either ADLs and/or IADLs.

#### **A. Definitions**

Strong Enough - Respondent-defined.

Supervision - Respondent-defined.

Personal Safety - Respondent-defined.

#### **B. Instructions**

1. Complete Check Item H17 by referring to question 8a for activities A. bathing, D. getting in/out of bed/chairs, and using the toilet. If "Yes" is marked in 8a for any of these activities, mark the corresponding Box in Check Item H17. If "Yes is not marked in 8a for any of these activities, mark Box 4 "all others" in H17.
2. Ask question 35 of proxy respondents only. Insert the name of the Sample Person or the relationship of the Sample Person to the proxy. For example, "Does Mr. Jones..." or "Does your father...". Since SPs may be offended by this question, use your own judgement about asking 35 of the proxy if the Sample Person is present. If you don't ask it, footnote the reason. For example, if you are using a proxy because the present Sample Person cannot respond due to cerebral palsy, you may chose to not ask the question. Whereas, if you use a proxy because the present Sample Person is deaf and dumb, you probably should ask.

### **CHECK ITEM H18 REVIEW OF RECEIVING HELP**

Check Item H18 reviews the activities for which the SP either receives help or supervision. Checking these activities here will reduce the amount of times you will have to look back into the ADL and IADL series during the next few questions on helpers.

#### **B. Instructions**

1. Refer to questions 8a and 9a (on pages 38 and 39) for ADL activities A-G. If "Yes" is marked in 8a or 9a for the activity, mark the corresponding Box in Check Item H18. Next, refer to questions 22a and 23a (on pages 46 and 47) for IADL activities H-O. If "Yes" is marked in 22a or 23a for the activity, mark the corresponding Box in Check Item 18. IF after reviewing 8a,

9a, 22a and 23a, you mark none of the corresponding "Yes" boxes in H18, mark the last box in H18 ("All Others") and skip to Check Item H20.

2. If ANY of the "Yes Boxes are marked in Item H18, continue with question 36.

### QUESTION 36 USUAL HELPER(S)

#### A. Instruction

Insert the activities marked in Item H18 when asking question 36. There is space to record up to four helpers. If there are more than four helpers, probe for the four that help the most. Enter the name or a description of each helper in separate columns. The names or descriptions will be used as references in the questions that follow, so record them in a way that will be salient to the Sample Person. First or last names are acceptable, as are relationships to the Sample Person. A name and a description will be useful if there are two or more helpers who can be described the same way. Job titles might be used for paid helpers. Examples of descriptions are:

My son  
My daughter, Helen  
My son's wife  
My oldest son's wife  
My neighbor, Sam  
The nurse from the VNA  
Mrs. Jones from church

### QUESTIONS 37 AND 38 ASSISTED ACTIVITIES AND HELPER DESCRIPTIONS

#### Instructions

1. Record in question 37 the activities for which the SP receives help from that helper. All activities marked in item H18 must be accounted for. If one or more are not accounted for by the time you are done asking question H37 for the last helper, probe by asking: "Who helps you with...?" and mark that activity in the appropriate column(s).

If there is only one helper or only one activity marked in H18, verify the situation with the respondent and mark question 37 without asking.

2. Mark in question 38a the one category that best describes the relationship of the helper to the Sample Person. If you are interviewing a proxy, mark the relationship to the Sample Person, not the proxy respondent. For example, if the son of a Sample Person is serving as a proxy for his mother and says "my father" mark "spouse" not "parent," since that is the relationship of the helper to the Sample Person.

**QUESTIONS 39 - 41**  
**PAYMENT FOR HELPERS AND AMOUNT OF HELP**

**Instructions**

1. Questions 39 a and b if the help that they receive is paid for and, if so, who pays for the help. Do not ask this question for helpers who are either a parent, child, or spouse of the Sample Person and unpaid volunteer. Home health care is often paid by a combination of sources: mark all the responses that apply in 39b.
2. Categories 01 and 02 refer to out of pocket expenses that are not reimbursed by an insurance program or health plan.
3. PRIVATE HEALTH INSURANCE (03) includes major medical policies, Medicare supplemental policies, and long term care policies.
4. WORKERS COMPENSATION should be marked as EMPLOYER (07).
5. CHAMPUS and CHAMPVA are examples of VA PROGRAMS (09).
6. In question 40, record the number of days that the helper helped in the past two weeks, even if those weeks were not typical. Be sure to record days in the past two weeks, not the past week.
7. In question 41, record the total number of hours per day that the helper usually helped. Record hours that the helper was available to provide supervision, in addition to hours spend providing hands-on care. If the helper's hours varied from day to day, record the average number of hours per day.

**QUESTIONS 42 - 44**  
**MAIN HELPER QUESTIONS**

**Instructions**

1. After completing 37-41 as appropriate for each helper named in 36, mark Check Item H19 to indicate the number of helpers.
2. Record only one main helper in question 42. The "main helper" is whomever the respondent considers it to be. If there was only one helper, he/she is considered the main one and question 42 will be skipped from Check Item H19.
3. Ask question 43 to determine if someone other than the main helper has assisted the SP specifically so that the main helper could take a break. This substitute assistance can be for any length of time.
4. Question 44 asks about satisfaction with various characteristics of the main helper. For a proxy interview, ask about the Sample Person's satisfaction. Do not ask 44e-g if the helper is present during the interview or a relative of the Sample Person.



**QUESTIONS 45 - 47  
SP HOME ALONE**

**Definitions**

**Problem** - Needs help or feels afraid when home alone.

**QUESTIONS 48 AND 49  
HELP WITH CARE**

**A. Objective**

The purpose of these questions is to obtain information on the informal support network available to the SP, if needed.

**B. Instructions**

1. If you know that the Sample Person lives alone, do not read the phrase, "Including the other person living here" when asking questions 48a and 49a.
2. For 48b and 49b, probe to obtain the appropriate description if it is not volunteered.
3. If more than one person would take care of the Sample Person if necessary, ask which person the SP would first ask for help and mark only one box in 48b or 49b.

**CHECK ITEMS H20 - H22  
NEED HELP OR MORE HELP**

**Instructions**

1. Refers to pages 38-39 questions 8e and 11 to mark Check Item H20. If the "Yes" Box is marked for either of these questions, in any of activities A through G, mark Box 1 and skip to question 50. If "Yes" is not marked in 8e or 11 for any of the activities A-G, mark Box 2 and go to Check Item H21.
2. Refer to question 22e on page 46 to mark Check Item H21. The "Yes" Box is marked in 22e for any of activities H through O, mark Box 1 and skip to question 50. If "Yes" is not marked in 22e for any of activities H-O, mark Box 2 and go to Check Item H22.
3. Refer to question 25 on page 46 to mark Check Item H22. If the "Yes" Box is marked in 25 for any of activities H through O, mark Box 1 and continue with question 50. If "Yes" is not marked in 25 for any of activities H-O, mark Box 2 in H22 and skip to question 53.

**QUESTIONS 50 - 54  
HIRING OR FINDING HELP**

**Instructions**

To get as complete an answer as possible, read the answer categories in 50b, 51, and 54b to the respondent if necessary. Mark all that apply.

**QUESTION 55 PROBLEMS  
BECAUSE SP HOME ALONE**

**Instructions**

1. In question 55a, insert the appropriate phrase in brackets depending on whether the SP is institutionalized or not. If the SP is in an institution, insert the appropriate type of institution. For example, hospital, nursing home, etc.
2. For 55b, be as inclusive as possible. If and, if necessary, read the answer categories to prompt the respondent.

**QUESTION 56 FAMILY  
ADAPTATIONS BECAUSE OF SP'S HEALTH**

**A. Objective**

This question identifies the impact of the Sample Person's health on the family. **These include:** leaving or changing jobs, reducing work hours or not working at all.

**B. Definitions**

Family - Anyone related to the Sample Person by blood, marriage, or adoption. **This includes both** related persons living with the Sample Person and related non-household members.

Ever - At any time in the Sample Person's life.

**C. Instruction**

Include changes that occurred for any reason related to the SP's health, such as in order to provide care for the SP, take the SP to medical or other appointments, etc.

## SECTION I. OTHER SERVICES

The questions in Section I ask about other services the Sample Person may have received from a variety of therapists, nurses, attendants, and other professionals.

### A. Definitions

Audiologist - A person skilled in working with hearing problems. These include: identifying a hearing problem; determining the range and nature of the hearing problem; training the person to deal with the problem, such as lip-reading and counseling other family members on how to deal with the problem.

Personal Care Attendant - A paid individual whose main responsibility is providing assistance and personal care to the individual, e.g., assistance with eating, bathing, and dressing.

Physical Therapy - Therapy to develop, improve or restore gross motor movements, such as walking.

Occupational Therapy - Therapy to develop fine motor skills which usually involves the use of hands or arms. It may involve working on activities like dressing, eating, and writing. It differs from physical therapy in that physical therapy deals with gross motor movements such as walking.

Adult Day Care Centers/Day Activity Center - Programs provided at an adult day care center, senior center, or similar facility or within an institution for the mentally retarded where services include: (a) vocational activities, (b) leisure activities (hobbies, exercise, trips, adult education classes), and/or (c) supportive services (health services, nutrition, transportation, and social work).

Vocational rehabilitation services - Vocational rehabilitation is a process of restoring persons with disabilities to the highest level of economic functioning of which they are capable. The process involves the delivery of a wide variety of goods and services needed by such individuals to make them employable.

Reader or Interpreter - Persons who read to others or provides assistance to hearing impaired, not for language difficulty.

Visiting Nurse - A nurse who provides medical services for the individual in their own home.

Prescription Medicine - (1) Any medicine obtained on a doctor's written prescription, (2) any medicine prepared on the basis of a doctor's telephone call to a pharmacist, or (3) any medicine, including injections given by a doctor (or nurse) to the person to take at home or administered in the office, hospital or clinic. Exclude medicine recommended by a doctor if no prescription is written. Also exclude vitamins, oxygen, and medicine taken through an IV (intravenous).

General Practitioner - A medical doctor who provides comprehensive medical care to patients of any age or sex regardless of the specific nature of the health problem.

Internist - A medical doctor specializing in medical care of patients of any age or sex with "internal" diseases, conditions, etc.

Family Doctor - See "General Practitioner".

Health Care Professional - Respondent-defined, but may include doctors, nurses, psychologists, medical technicians, chiropractors, dentists, or anyone else working the health care field.

Prescribed - Ordered by a doctor or other health care professional. These may be written prescriptions for medications and supplies, or instructions given orally or in writing for home medical treatments.

Mental Health Counselor/Therapist - See definition on page 7-9.

Emergency Basis - See definition on page 7-23.

Regular Basis - See definition on page 7-9.

Transportation Services - See definition on page 7-13.

Coordination of Services (Medical and non-medical) - See definition on page 7-19.

Outpatient Services - See definition on page 7-23.

## **B. Instructions**

1. If the response to question 5 is "Yes", probe to determine whether all was trained or only some were trained.
2. Repeat the lead-in for question 11 anytime there is a break in the continuity of asking a-h, such as when the respondent explains an answer rather than simply answering Yes or No.
3. If asked about the meaning of "problems" in question 12, read the answer categories in question 13 as examples of problems.
4. If you mark Box 1 "Receive help" in question 14, read the parenthetical "More" when asking 15 and 16.
5. In question 18, probe for the specific type of doctor seen most often if not volunteered by the respondent. If two or more types of doctors are seen equally, ask which is considered the "main" doctor and mark only one box.
6. If Box 1, 2, or 3 is marked in 18, insert that type of doctor when asking 19-25. For example: "Have you seen this internist in the past 12 months?" If Box 4 or 8 is marked in 18, insert "Doctor" when asking 19-25.

7. The specialists in question 26 are listed in alphabetical order with their more common names/descriptions in parentheses. If necessary, read the list to the respondent. Read the titles only, the titles and common names, or the common names only depending on the respondent.
  - a. Mark all that apply in 26a.
  - b. If only one specialist is marked in 26a, transcribe the number of that box to the space in 26b without asking. However, if more than one is marked in 26a, ask 26b and record the number of the corresponding box in 26a to the space in 26b. If 2 or more specialists are seen equally, ask for and record the number of the one considered to be the "main" specialist seen.
8. If the entry in 26b is 01-21, insert the corresponding type of specialist when asking 27-33. If 01-21 is not entered in 26b, insert "Doctor" when asking 27-33.
- 9a. If Box 1, 2, or 3 is marked in 18, insert the corresponding title when asking question 34. If Box 1, 2, or 3 is not marked in 18, insert "Family doctor" when asking 34.
- b. If the entry in 26b is 01-21, insert the corresponding title when asking question 34. If 01-21 is not entered in 26b, insert "specialist" when asking 34.

**Examples:** During the past 12 months, which doctor have you seen the most often --

"The general practitioner or the podiatrist?"

"The family doctor or the specialist?"

- c. If one doctor was seen in the past 12 months and the other one was not (per questions 19 and 27), verify this with the respondent and mark Box 2 or 3, as appropriate, in 34. (If neither was seen in the past 12 months, mark Box 1 in 34.)
  - d. If both doctors were seen equally in the past 12 months, ask which is considered to be the Sample Person's "main" doctor and mark that Box in 34. Also, footnote that both were seen equally in the past 12 months.
- 10a. If the doctor seen the most in the past 12 months could not be determined in question 34, rephrase the introduction to question 35 as:

"Now, I'm going to read you a list of items which concern visits to your main doctor."

- b. Repeat the introduction as necessary when asking 35 a-1 to remind the respondent of which doctor those questions refer to.
- c. Read the parenthetical, "Would you say ..." if the respondent gives inappropriate responses, such as "It's ok", "I never have a problem with that", "He does a nice job", etc.

- d. Many of the statements in question 35 apply to the staff in the doctor's office as well as to the physician. For example, consider the doctor, nurse, and technician in 35a if all three participate in the examinations. Likewise, if only the clerical staff handle the insurance claims, consider only them in 35l.
  - e. If a particular aspect does not apply, mark "NA". For example, if all visits are to an HMO clinic, there will be no insurance claims. Mark "NA" for 35l.
  - f. If the respondent is unfamiliar with a particular aspect of the visits, mark "DK". For example, if a proxy respondent does not know how thoroughly they examine the Sample Person, mark "DK" for 35a.
- 11. Repeat the lead-in to question 36 as necessary to remind the respondent of the qualifications of the question --- that is, told by a medical professional and resulted because the Sample Person did not have follow-up care.
  - 12. Ask questions 37-41 as appropriate for each service, one at a time. Refer to page 7-13 for instructions on completing these items.
  - 13. Questions 42-46 are similar to 37-41; there are only slight wording changes in the questions. Again, refer to page 7-13 for instructions.
  - 14. Questions 48-60 concern mental health services. Refer to pages 7-23 and 7-24 for instructions on completing these items.
  - 15. Questions 61-70 concern coordination of medical and non-medical services. Refer to page 7-19 for instructions on completing these items.
  - 16. Ask questions 71 only if the Sample Person received services from a center for Independent Living ("Yes" in 42a for services 1c on page 71).

Repeat the lead-in as often as necessary to remind the respondent that these services must have been received from a Center for Independent Living.

- 17. Ask question 72 only if the Sample Person received services from an Adult Day Care or Day Activities Center ("Yes" in 37a for service I on page 65).

## SECTION J. SELF-DIRECTION

### A. Definitions

Refer to pages *7-14* to *7-16* for applicable definitions.

### B. Instruction

Refer to pages *7-16* to *7-17* for applicable definitions.

## SECTION K. FAMILY STRUCTURE, RELATIONSHIPS AND LIVING ARRANGEMENTS

### A. Objective

This section obtains information about the Sample Person's marital status, family and household composition, and his/her social and financial interaction with children and other family members. This information, when compiled with health data, will be used to identify the factors enabling certain persons to remain at home rather than enter an institution.

### QUESTIONS 1 AND 2

### B. Instructions

1. Probe to determine on whether a spouse resides in the household or not, if it is not obvious. Situations where the spouse may not be living in the household include:
  - The spouse lives elsewhere most of the time because of service in the Armed Forces or in connection with a job.
  - The Sample Person (or the spouse) moved to be closer to a source of medical treatment.
  - The Sample Person (or the spouse) moved in with another relative to get or give help.
2. Record persons who are not married, but are living together as husband and wife, as "Married - Spouse in HH."
3. If asked, explain that "separated" refers only to married persons who have a legal separation or who have parted because of marital discord.
4. Ask question 2 to determine how long the person has been in his/her current marital status. Mark the "less than 1 year" box or enter the number of years, including fraction if given.
  - Reword question 2a for persons who are not married but are living together as husband and wife to determine how long this arrangement has been in effect. For example, "How long have you been living together?"
  - Ask questions 2b only for persons who are widowed, divorced or separated, inserting the appropriate marital status from question 1.



## CHECK ITEMS K1 AND QUESTIONS 3 AND 4

### A. Instructions

1. Ask in 3 and record in 4 only persons currently living in the Sample Person's household. This includes: babies and small children; lodgers, boarders, and employees; anyone who usually lives there but is temporarily away, such as traveling or in the hospital; and anyone else staying there who does not have a usual residence elsewhere to which they may return. If in doubt, include the person as a household member, but footnote the situation in detail.
2. Be sure to include the Sample Person in both 3 and 4.
3. Enter the Sample Person on Line 1 of the question 4 table. The order for listing other household members is not critical, but a preferred order would be: Sample Person, spouse, children (by age), other relatives, unrelated persons.
4. Ask or verify 4b and c for each person listed.
5. Show all relationships to the Sample Person. For unrelated family groups, show both the relationships to the Sample Person and the relationships to each other. For example, "Housekeeper's son".
6. If there are more than 9 household members, record the first 9 in the question 4 table and the rest in the nearest available footnote space. Number these additional people as "10", "11", etc., and include in the footnote the same information as required in 4: full name (first/middle initial/last), sex (M or F), and the relationship of the person to the Sample Person.

## QUESTIONS 5-7 CONTACTS WITH OFFSPRING

### A. Definitions

Living Daughters/Sons/Children - The natural, step, and adopted offsprings of the Sample Person (this does not include foster children or wards of the Sample Person), currently living. This does not include live-borns who have since died.

Here - The apartment, house, trailer, etc. where the Sample Person currently lives. This also includes the hospital, nursing home, or other institution if the Sample Person is institutionalized. It does not include the place the Sample Person is temporarily staying if he/she is traveling, visiting, on vacation, or the like.

Routinely Gives Money - Periodic assistance with paying bills, covering living expenses, etc. This assistance should be in the form of cash or check to the Sample Person and not paying the bills directly, purchasing food or clothing, or paying the mortgage/rent/utilities. This assistance does not have to be on a regular basis, such as monthly, bi-weekly, etc., but should be more frequently than once a year or only on birthdays or holidays.

## **B. Instructions**

1. Ask questions 5a and 5b regardless of the Sample Person's age, health, household composition, or any other factors. Be sure to emphasize "Living".
2. Ask question 6 only for Sample Persons with one or more children, none of which currently live with the Sample Person. Choose the appropriate term for asking these questions:
  - If only one daughter, say "Your daughter"
  - If only one son, say "Your son"
  - If multiple children, regardless of gender, say "Any of your children"
- 3a. Record the response to each part of question 6 verbatim, with one exception - of seconds are reported in 6a, round to the nearest minute if the response is 60 seconds or more. If the response is 1-59 seconds, enter "1" and mark the "minutes" box. Do not try to convert the response to 6b-d to another time period, since these questions do not concern a specific time.
- b. If the frequency of contacts for 6 b-d varies (for example: "Sometimes once a month and sometimes once a week") ask the respondent to estimate the usual frequency, or if that is not possible, the average frequency. (This applies also to 6a if the elapsed time varies.)
- c. If elapsed time (6a) or frequencies (6b-d) differ between two or more of the Sample Person's children, enter the "fastest" (6a) or "most frequent" (6b-d).
4. See #2 above for wording question 7.

## **QUESTIONS 8-13 LIVING ARRANGEMENTS**

### **A. Definitions**

Living Brothers/Sisters - The full, half, step, and adopted siblings of the Sample Person currently living. This does not include live-borns who have since died.

Mother/Father - Respondent-defined. It may include the biological, adopted, step, etc. parent, or a foster parent or guardian the Sample Person considers the same as a mother or father.

### **B. Instructions**

1. Ask questions 8-10 only for Sample Persons who currently live with someone other than on in addition to a spouse. Determine this by referring to the Household Composition in the question 4 table on page 78 and completing Check Item K4.
2. Exclude the Sample Person's spouse from these questions. If the spouse is a household member, read the parenthetical when asking question 8. For questions 9 and 10, "these people", or "this person" refers to the person(s) 18+ years old other than the spouse living with the Sample Person.

3. Ask questions 11 and 12 for each Sample Person, regardless of the household composition. Be sure to emphasize "Living".
4. If the Sample Person's mother and/or father is listed as a household member in the question 4 table on page 78, mark "Yes" in 13a and/or 13b, as appropriate, without asking. Otherwise, ask 13a and/or 13b regardless of the Sample Person's age, health, household composition, or other factors.

**QUESTIONS 14-15**  
**CONTACTS WITH OTHER FAMILY MEMBERS**

**A. Definitions**

Family Member - Anybody related to the Sample Person by blood, marriage, or adoption, except the spouse and children (as defined above for questions 5-7).

Here - See definition on page 8-42.

Routinely Gives Money - See definition on page 8-42.

**B. Instructions**

1. Include the parenthetical when reading the introduction and asking questions 14a-d if previous questions indicated that the Sample Person has a living spouse and one or more living children, regardless of whether or not they are household members. Modify the parenthetical as necessary to fit the actual situation. For example, if the Sample Person has children, but no spouse, say "Other than your children".
2. If in response to 14a or volunteered that the Sample Person has no family (other than the spouse and/or children), mark Box 000 in 14a and skip to the next section.
3. See above instructions for questions 5-7.

## SECTION L. CONDITIONS AND IMPAIRMENTS

Questions in this section provide information about vision and hearing as well as information on other conditions and impairments which affect older persons. They are asked only of persons age 70+.

### General Definitions

EVER - Present at any time in the Sample Person's life.

NOW - Present as of the time of interview.

### CHECK ITEM L1 AND QUESTIONS 1-5 EYE CONDITIONS AND VISUAL IMPAIRMENTS

#### A. Definitions

Eyeglasses - Includes prescription eyeglasses as well as eyeglasses purchased at drug stores, etc., that did not require a prescription.

Prescription Eyeglasses - Eyeglasses which were obtained for the Sample Person under the direction or recommendation of an eye specialist, such as an ophthalmologist, optician, optometrist, etc. Do not include glasses the person uses that were prescribed for someone else. Also, do not include non-prescription sunglasses, safety glasses, or the like, which are worn for protection only.

Lens Implant - Artificial lenses which are surgically and permanently placed inside the eye. This is sometimes referred to as an intraocular lens.

#### B. Instructions

1. If the Sample Person is totally blind in both eyes, mark "Yes" in 1c and skip to 3.
2. If the response to 1e indicates that the person may only have trouble when he/she does not use glasses, reask the question, stressing the phrase "EVEN WHEN WEARING GLASSES." For responses to 1e such as "I don't have glasses," reask the question "Do you NOW have any other trouble seeing with one or both eyes?" deleting the last phrase.
3. If the respondent mentions in 2a that eyeglasses are only used occasionally, mark "Yes". For example, mark "Yes" for responses such as "I only wear them when I drive at night", "Only when I go to the movies", or "I only use them for reading". However, mark "No" in 2a if the respondent has eyeglasses but does not use them.
4. Handle question 2c, which concerns contact lenses, in the same manner as question 2a.
5. In question 5, the magnifying glass does not have to be prescribed. If the response is qualified in any way, such as "Only sometimes for very small print", or "I use a jeweler's loop for working on my hobby", consider this a "Yes" response.

**QUESTION 6**  
**DEAFNESS AND HEARING IMPAIRMENT**

**Instructions**

Ask question 6 concerning the Sample Person's hearing in the same manner as question 1 about the Sample Person's vision. Do not ask 6b and 6c if the Sample Person is totally deaf ("Yes" in 6a).

**QUESTION 7**  
**CONDITION LIST**

**A. Definitions**

All Conditions - Are respondent-defined. Do not attempt to explain any, even if you are sure you know about the condition.

Doctor - Respondent-defined and not limited to medical doctors. For example, accept it if the respondent says that the condition was diagnosed by a psychologist, dentist, chiropractor, or any other medical practitioner.

**Instructions**

1. Ask each of 7a (1) - (11) before going to 7b-d. Then ask 7b-d as appropriate for each condition marked "Yes" in 7a.
2. The wording of 7b is based on the condition being asked about. For conditions (1) and (10), use the first alternative - "In what year did (the condition) first noticed?"
3. If the onset of a condition is reported to have been in the 1800's, enter all four digits of the year (such as "1899") in 7b. Otherwise, enter only the last 2 digits.
4. Do not ask 7c or 7d for conditions with the answer spaces shaded.
5. If the Sample Person is taking medication(s) for the condition, consider him/her as still having the condition and mark "Yes" in 7d. For example, mark "Yes" in 7d (7) if the Sample Person says his hypertension is under control because of the medicine he takes.

**CHECK ITEM L3 AND QUESTION 8**  
**TYPE OF CANCER**

**Instruction**

1. Ask 8 only if "Yes" is marked in 7a (11).

2. Although the questions asks about the "kind" of cancer, the answer categories represent the sites of cancer. Because of this slight inconsistency, be sure the respondent refers to card A19 or you read each category to the respondent.
3. Probe as necessary of "skin cancer" is reported. Mark Box 02 if the respondent knows it was melanoma. Mark Box 03 if the respondent know it was not melanoma, and mark Box 04 if the respondent doesn't know if it was melanoma or not.

**QUESTION 9A  
DIZZINESS**

**A. Definition**

Dizzy/Dizziness - These terms are respondent-defined.

**B. Instruction**

For 9a, "trouble with dizziness" is respondent-defined. Do not probe to determine if the Sample Person has "trouble" for such responses as, "I sometimes have dizziness" or "Yes, I get dizzy". For such answers, mark "Yes" in 9a.

**QUESTION 10  
TROUBLE BITING OR CHEWING**

**A. Definitions**

Trouble biting/chewing - Respondent-defined.

**B. Instruction**

Question 10 concerns biting/chewing trouble with any kinds of food, not just the two examples in the question. For example, mark "Yes" if the Sample Person has trouble with sticky foods ~~that tend~~ to loosen his/her dentures while biting or chewing.

## SECTION M. HEALTH OPINIONS AND BEHAVIORS

### A. Objective

This section is designed to help meet the present need for information about both the psychological and physiological aspects of aging. The section will also provide some indication of the Sample Person's self-perceived health status, as well as health behaviors. Sample Persons who are less than 70 years of age will not be asked these questions.

### QUESTION 1 HEALTH OPINION

### B. Instruction

1. If the respondent gives an answer other than one of the five choices, such as "pretty good", or otherwise shows that he/she does not understand the questions, repeat the entire question, emphasizing "in general" and clearly stating the five choices. If the respondent still gives an unacceptable answer, footnote it without marking a box. In no instance should you try to interpret the response or choose an answer for the respondent.

### QUESTION 2 DEPRESSION IN PAST YEAR

### A. Instructions

1. Ask question 2 only of Sample Person's to determine the degree of sadness or depression that he/she has experienced over the past year. If asked, "the last year" refers the past 12 months.
2. Skip question 2 and continue with question 3 for a proxy respondent.

### QUESTIONS 3 AND 4 PHYSICAL ACTIVITY AND EXERCISE

### A. Objective

Physical activity and exercise is an important aspect of health maintenance and may be an indicator of health status.

### B. Definitions

Physical Activity - This term is respondent-defined.

Exercise - Physical activity which the person consciously performs for the sake of his/her well being. The exercise does not have to be part of a formal program or prescribed activity. Include any kind of exercise, such as walking, physical fitness programs, sports, etc.

Regular Routine - Physical exercise performed on a recurring basis at fairly even intervals, consisting of some set type of physical activity. Examples are golfing every Thursday, walking around the block twice daily, or any other activity performed routinely for exercise.

**C. Instructions**

1. If asked, "one year ago" in question 3 means this same general season or period, about 12 months ago.

**QUESTIONS 5 - 7  
HEIGHT AND WEIGHT**

**A. Objective**

Height and weight will be used to determine whether people have weight problems that can be related to other health characteristics. Average heights and weights can be calculated for various groups of people based on age, sex, race, and other characteristics.

**B. Instructions**

1. Enter the response verbatim, including fractions; for example, "5 feet, 6-1/2 inches," or "122-1/2 pounds." Do not attempt to estimate the Sample Person's height or weight from observation.
2. Enter a dash (-) on the inches line for even heights; for example, "6 feet, - inches." Enter a dash (-) on the feet line if the height is reported in inches only. For example, "\_\_\_ feet, 68 inches".
3. Ask question 7 of self respondents only. If the Sample Person says, "I don't know. It fluctuated a lot," probe for the Sample Person's usual weight at age 50.
4. If the height and/or weight is reported in the metric measurement system, (meters, centimeters, kilograms, etc.) rather than in feet, inches, or pounds, footnote the exact metric response. Do not enter metric measurements in questions 5 through 7 or attempt to convert the response to feet, inches, or pounds.



**QUESTIONS 8 - 13**  
**TOBACCO AND ALCOHOL CONSUMPTION**

**A. Objective**

Questions 8 through 13 ask about the Sample Person's tobacco and alcohol consumption. These questions will be used to look at associations between these behaviors and health.

**B. Definitions**

Cigarette - Respondent-defined, but does not include marijuana, hashish, or cigars.

Past Year - The last 12 months.

**C. Instructions**

1. If Box 3 "Not at all" is marked in question 9, read the second alternative "Did you smoke" when asking question 10. In all other situations, read the first alternative "Have you smoked". If the Sample Person started and stopped at various times over the years, determine the total years by adding together all smoking periods.
2. Question 12 concerns usual drinking patterns across the 12 month period, such as "so many days a month" or "so many days a week". Enter days per year only if there is no weekly or monthly pattern.
3. For question 13, consider "a drink" to be 1 bottle, can, or glass of beer, 1 glass of wine, or about 1-1 1/2 ounces of liquor either straight or mixed.

## SECTION N. COMMUNITY SERVICES

### A. Objective

This section concerns types of social services and activities which provide support so that persons who need help may remain in their homes rather than enter institutions. These questions determine participation in and frequency of use of these community services during the past 12 months. Sample Persons who are less than 70 years of age will not be asked these questions.

### B. Definitions

Meals on Wheels - A service which delivers hot meals to persons in their home.

Special Meal Program - Meals provided by some program or group on a regular or daily basis at a location outside of the participants' homes.

Homemaker Service - A program which provides help in the home with cleaning, cooking and sometimes shopping.

Health Aide - An individual, not a R.N. or a doctor (as defined by HIS), employed in the health profession to provide medical or health assistance to people in their homes.

Information and Referral Services - A service that provides information on how and where to get assistance or background information on specific topics, like crisis centers, home care, the latest medical treatment for various conditions, etc.

### C. Instruction

1. Ask 2 immediately after each "Yes" response in question 1.
  - a. It is possible that some of the services may overlap, for example, "group meals" may be served in a "senior center." Count each of these as a separate service, if so reported.
  - b. Most of the listed services in question 1 are self-explanatory; however, if questions arise, explain to the respondent that we are interested in non-profit public or privately sponsored programs that provide services on a community basis. There may or may not be a fee or eligibility requirements involved. For example, if someone hires a RN, LPN, or maid through an employment agency to help with personal care or housework or a neighbor volunteers to do the work, this would not be considered a community service. But if a church or county health department provides the same service, with or without a fee, this would be considered a community service.

Some of these services, such as a health aid, may be utilized because the person is ill or has disabilities, not just because of age. Include the service if personally used by the Sample Person regardless of the reason.

2. When you receive a "Yes" response to any part of question 1, immediately ask question 2 for that service before continuing with the list. After marking an answer box in 2, reask the lead-in phrase in question 1 before continuing with the list.
  - a. The terms "frequently," "sometimes," and "rarely" are respondent-defined.
  - b. If you are asked, this question refers to how often the Sample Person used the service when it was used. For example, if the reply is "I broke my leg and had a health aide come in every day for 3 weeks," the response should be based on the frequency of use, as defined by the respondent, during those 3 weeks.

## **SECTION O. UPDATE CONTACT PERSON INFORMATION**

### **A. Objective**

The contact information collected here will enable the NCHS or Census to make further contact with the Sample Person should it be required.

### **B. Instructions**

1. Mark Check Item 01 based on the information printed on the cover label. If there is already a contact person listed on the label, ask 1a to verify that the information on the label is correct.
2. Ask 1b if there is no person on the label, and record that information in 2.

## **SECTION P. INTERVIEWER OBSERVATIONS**

### **A. Objective**

This section is designed to obtain a better understanding of how well the respondent was able to complete the interview and the burdens that may have been encountered in doing so.

### **CHECK ITEM P1 AND QUESTION 1 RESPONDENT AND PROXY RESIDENCE**

#### **Instructions**

1. If there was more than one person assisting the SP with the interview, answer question 1a in relation to the person you think was the main assistant.
2. In question 1b indicate the relationship of the proxy respondent to the SP.
3. Refer to household composition to determine if the proxy or assistant resides in the same HH as the SP.

### **QUESTION 2 REASON FOR PROXY.**

#### **Instruction**

1. Mark as many "Yes" categories as needed in question 2 to indicate exactly why a proxy or assistant was needed to complete this interview.

**QUESTION 3-7**  
**FRS OPINIONS**

**A. Definition**

Respondent - The person who answered the DFS-2 questions. This will be the Sample Person he/she responded with or without assistance, or the proxy respondent if one was used. If more than one proxy responded, this refers to the ONE you consider to be the main respondent.

**B. Instruction**

These questions ask for Your opinion of the respondent and interview. If you are in a situation where the respondent can see your entries, complete questions 3-7 immediately after leaving. Do not wait to complete them during your at-home edit.

## CHAPTER 9. DFS-3 ELDERLY QUESTIONNAIRE

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### BACKGROUND

Elderly Americans are major users of health care services in the United States. Because health care expenses are greatest during periods of declining health, disability and institutionalization, the maintenance of good health and functional independence among the elderly is one of the most important goals of health promotion and disease prevention in our aging society.

Data from the DFS-3 questionnaire will be used to describe the health status of elderly persons age 69 or older and to assist in forecasting health policy choices for the next decade.

The DFS-3 questionnaire contains a subset of the questions asked in the DFS-2. Therefore, the instructions that were given for the DFS-2 will be the same for the DFS-3. However, because not all questions from the DFS-2 are in the DFS-3, the question numbers differ somewhat. Rather than reproduce a full set of instructions for the DFS-3, we have provided a chart of the questions from the two questionnaires so that you can reference the instructions in Chapter 8 as needed when administering the DFS-3.

<u>DFS-3</u>		<u>DFS-2</u>	<u>Manual Reference</u>
<u>A</u>	<u>Housing</u>	<u>A</u>	
1-5		1-5	8-3
6		7-7	8-4
7-11		8-12	8-5
12		15	8-6
<u>B</u>	<u>Transportation</u>	<u>B</u>	
1-2		1-2	8-8
3		6	8-8
<u>C</u>	<u>Social Activity</u>	<u>C</u>	
1		1	8-10
2		3	8-10
3		4	8-10

<u>DFS-3</u>	<u>DFS-2</u>	<u>Manual Reference</u>
<u>D Work History/Employment D</u>		
1	1	8-11-8-12
2	16	
3	18	
4	39	
5	57	
6	58	
7	6	
8	7	
<u>E Assistive Devices F</u>		
1-2	1-2	8-15
3	4	
<u>F Health Insurance G</u>		
1-6	1-6	8-16
<u>G Assistance with Key Activities H</u>		
1-14	1	8-17
15	16	8-24
16	18	8-25
17-26	19-28	8-25 through 28
27	31	8-30
28	34	8-31
29	35	8-31
30-36	36-42	8-32-8-33
37	44	8-33
38-39	48-49	8-34
40	55	8-35
<u>H Other Services I</u>		
1-12	1-2	8-36-8-39
13	25	
14	37	
15	38	
16	39	
17	40	
18	41	
19	47	
20	70	



<u>DFS-3</u>	<u>DFS-2</u>	<u>Manual Reference</u>
	Family Structure, Relationships and Living Arrangements	
<u>I</u>	<u>K</u>	
1-15	1-15	8-41-8-44
	Conditions and Impairments	
<u>J</u>	<u>L</u>	
1-10	1-10	8-45-8-47
	Health Opinion and Behavior	
<u>K</u>	<u>M</u>	
1-13	1-13	8-48-8-50
	Community Services	
<u>L</u>	<u>N</u>	
1-2	1-2	8-51
	Contact Person	
<u>M</u>	<u>O</u>	8-53
1-2	1-2	
	Interviewer Observations	
<u>N</u>	<u>P</u>	8-54
1-7	1-7	

## CHAPTER 10. DFS-4 POLIO SURVIVORS

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### A. Objective

The purpose of the DFS-4 is to generate an estimate of the prevalence of post-polio syndrome and also to establish a national dataset with information about the late effects of polio to inform researchers about its history. These data also will prove to be invaluable for public health officials in other countries where new cases of polio continue to be a significant problem.

### B. Instructions

The DFS-4 questionnaire will be administered to persons who reported having had polio in the original HIS interview. In most cases, these polio survivors will be interviewed on a DFS-1, 2, or 3 questionnaire; however, there may be some who will only get the DFS-4.

1. If the DFS-4 was assigned along with one of the other questionnaires for the same Sample Person, use the same respondent for both questionnaires.
2. If, however, the DFS-4 does not have a DFS-1, 2, or 3 for the same Sample Person, follow the same rules as for the other questionnaires:
  - If the Sample Person is under 18, ask to speak with the person who knows the most about the Sample Person's health.
  - If the Sample Person is 18+, interview him/her if possible; otherwise, ask to speak with the person who knows the most about the Sample Person's health.

### C. Definitions

Weakness -- Respondent-defined

Difficulty passing urine -- Respondent-defined.

Admitted to the Hospital--Overnight stay in the hospital. Admission to the hospital does not include emergency rooms, or outpatient clinics unless the visit resulted in an overnight stay.

Spinal tap--The insertion of a needle into the spine in the central part of the lower back to withdraw fluid. Typically used to diagnose meningitis.

Mechanical ventilator--A machine linked to the breathing tube of a patient with weak breathing muscles which pumps air into the lungs.

Assistive devices--Devices prescribed by a physician or physiotherapist to support and improve the function of a weakened limb or other part of the body (e.g., a leg brace.)

Physical therapy--Refers to therapy to develop or work on gross motor movements, such as walking. This does not include visits to a chiropractor.

Regularly--On a routine basis or following a set schedule.

Occasionally--Following no set schedule or taking place less than once a week.

Surgical operations--Examples of surgical operations specific to polio include: an operation to shorten a limb, to lengthen a tendon, or to support an unstable joint.

Severe injuries--Respondent-defined, but must have limited the ability to carry out daily activities.

New polio related difficulty--New onset of pain or weakness or impaired mobility related to a part of the body previously effected by polio.

Pain--Respondent-defined.

## QUESTIONS 1-19 ONSET OF POLIO

### A. Instructions

1. Unlike items in the other DFS questionnaires, include fractions if reported in response to question 1. If the Sample Person got polio when less than 1 month old, mark the "Less than 1 month" box. If the respondent is not sure about the age of onset, enter an estimate on the line and footnote the situation. If the Sample Person never had polio, mark the "Never had polio" box and end the interview. For Final Status in Part II, Item A, mark box 00 - "Never had polio" and complete items B, C, and D as appropriate.
2. Enter all dates in 2 digit numbers for month, day, and/or year.
3. There is a change in reference periods between questions. For example, question 4 refers to the first two weeks the Sample Person had polio, whereas questions 5 and 6 refer to the first month of illness. Questions 7 through 11 refer to the time at which the polio was diagnosed. Emphasize the reference periods when asking these questions.
4. If you mark box 3 "Something else" in question 11, enter the name or a detailed description of the kind of help provided.
5. Record fractions, if reported in question 12b.

6. When asking question 13a, read the answer categories regardless of whether or not the respondent is referring to the flashcard. Repeat the answer categories in the remaining parts of question 13 only as necessary; that is, when the respondent gives another answer such as "no problem", "pretty bad", and the like. Repeat the reference period for question 13 whenever necessary.
7. When asking question 14, read all the answer categories before allowing the respondent to answer. Mark only one answer.
8. In question 15, mark all forms of physical therapy and exercise which were administered to the Sample Person as part of rehabilitation. If you mark "other", write the names or detailed descriptions of the exercises on the specify line. Continue in the notes space if more room is needed.
9. If the duration of the program reported in question 17 is less than 1 year, mark the "less than 1 year" box; otherwise, enter the whole number of years on the "years" line. Round up to the nearest whole year if the time is reported in months. For example, record "2 years" for a response of from 18 months to 29 months.
10. For each surgical procedure, enter in 19, the age in whole years at which the Sample Person underwent the procedure. Then enter the name or description of each surgical procedure performed to correct a polio related weakness or limitation.

If the respondent reports more than 3 surgeries, probe to discover which 3 were the most serious.

## QUESTIONS 20-29 PHYSICAL BEST

### A. Objective

This set of questions collect detailed information about the time in the polio survivor's life when he or she was at his or her physical best in order to measure improvement and decline in the quality of the polio survivor's life. Physical best refers to the period after getting polio when strength and endurance were at a peak and the Sample Person is or was in the best possible condition to carry on activities of daily living such as working, housework, walking, driving, dressing, bathing and so forth.

### B. Instructions

1. Question 20 is asked to determine the age or ages when the Sample Person was at his/her physical best.

- If a single age is given, record it in both answer boxes. For example: if the sample person was at his/her physical best at age 25, record

25 to 25 Years of age

- If a range of ages is given, record the lower age in the first (left) answer box and the higher age in the second (right) answer box. For example: if the Sample Person was at his/her physical best between the ages 28 to 32, record

28 to 32 Years of age

- If the Sample Person is currently at his/her physical best, mark box 9977 "presently at physical best" and do not enter any ages.
  - If the Sample Person has never had a physical best, mark box 9988 "Never had a physical best."
  - Mark box 9999 "DK" if the respondent doesn't know if or when the Sample Person was at his/her physical best.
2. Read all answer categories when asking questions 21, 25, and 26. Read the answer categories in 22 through 24 only in a telephone interview. Since all these questions permit only one answer each, read all answer categories before allowing the respondent to answer.
  3. If there is a break in the continuity of question 27, advise the respondent of the change in the reference period by saying, "During the period of your physical best, did you use a --".
  4. Complete question 28 the same as 13. See page 10-2.
  5. Record the person's weight in question 29 in whole pounds only.
    - If the respondent tells you, or if you know from previous responses that the sample person was pregnant during her physical best, probe for her weight before she became pregnant and record it on the answer line. Footnote "pregnant" and the person's weight while pregnant. Never probe to determine if a person was pregnant, however.
    - If the weight is reported in the metric measurement system (grams or kilograms) or other measurement (stones), rather than in pounds, leave the pounds line blank and footnote the response. Do not enter a measurement other than pounds or attempt to convert the response to pounds.

**QUESTIONS 30-40**  
**PERIOD OF TIME AFTER PHYSICAL BEST**

**A. Objective**

This set of questions deals with the period of decline after having achieved a physical best. These questions deal with the loss of abilities, weight loss and gain as well as new injuries incurred. These questions will provide information about the onset of post-polio syndrome and other late effects of polio.

**B. Instructions**

1. Complete question 33 by entering the number of pounds either gained or lost, not the Sample Person's weight. Enter whole pounds only. If reported in another unit, leave the answer space blank and footnote the exact response.
2. Complete question 35d in the same manner as question 19. (See page 10-3)
3. Enter ages in question 38 in whole years only. Then describe the injuries. A description of the accident which caused the injury is not necessary. If the Sample Person had more than four injuries, probe to discover which four were the most serious injuries.
4. Question 39 concerns the speed with which new polio related difficulties developed to the extent that they had an effect on the Sample Person's life. Read all of answer categories 1-5 before the respondent answers.
5. In question 40, be sure to differentiate to the respondent that you are asking about NEW conditions. Also, emphasize the change from weakness to pain as well as from muscles to joints. If in 40a, 40c, or 40e, the respondent asks you what is meant by muscle weakness, muscle pain, or joint pain, read the parts of body mentioned in 40b, 40d, or 40f as examples of each condition.

**QUESTIONS 41-51**  
**PRESENT EFFECTS OF POLIO**

**A. Objective**

This set of questions asks about the effect polio is currently having on the respondent's life. Coupled with answers to similar questions about onset, after onset, physical best, and so forth, this information will help analysts paint a complete portrait of the disease.

**B. Instructions**

1. Complete question 41 the same as question 13. (See manual page 10-2)
2. For questions 42, 43, 45, and 49, read all categories before the respondent answers.
3. If you are conducting the DFS-4 interview with a proxy respondent, mark box 0 "proxy" in 48 and skip to question 50.
4. Ask all of question 50 a-r (as appropriate) before going to 51. Then, ask question 51 for each "yes" in 50. Don't try to define or explain any of these conditions to the respondent. If the respondent is not familiar with a condition or doesn't know if a doctor ever diagnosed it, mark "DK".

**QUESTIONS 52-55  
POST-POLIO SYNDROME**

**A. Instructions**

1. Do not ask question 54 and 55 of a proxy respondent. Otherwise, complete 54 similarly to question 13. (See page 10-2)
2. Question 55 is different from all other questions in that you are asking the Sample Person to assign a scale of 1 to 7 to his/her satisfaction with life. Repeat the question as often as necessary for the Sample Person to understand what is expected of him/her. If after a reasonable amount of probing, the respondent is still unable to answer, write "DK" in the answer space and do not mark a box.

**CHECK ITEM P3 - QUESTION 57**

**A. Objective**

This set of questions collects information about a contact person to be used in the event that more information is needed, or further interviews will take place.

**B. Instructions**

Mark Check Item P3 based on the status of a DFS-1, 2, or 3 questionnaire for this same Sample Person. You will not have to reask these questions if the contact person was verified/obtained in the DFS-1/2/3 interview. If you do have to complete these in the DFS-4, refer to instructions for similar items in the DFS-1. (See page 7-27)

**QUESTIONS 58-60**  
**FACILITY/PROVIDER INFORMATION**

**A. Objective**

The DFS-4 data analysts would like to review the medical records of polio survivors. They can do this, however, only with the permission of the Sample Person.

**B. Instructions**

1. If the Sample Person will not give permission for researchers to access his/her medical records, there is no need to complete 58b-59b. Mark box 2 "No" in 58a and end the interview. In Part II, Final Status on the inside front cover, mark "complete" unless there is another set of questions in the DFS-4 that were refused by the respondent. (Marking "No" in 58a and skipping 59b-60 and the Provider Permission Form does not make this a partial interview.
  - a. Ask 58b and mark box 0, 1, or 9 as appropriate. If you mark box 1, enter the complete name and address of the hospital. If appropriate, suggest that the respondent refer to whatever sources available to get the hospital's name and address. Enter "DK" for any missing parts. After the interview, enter the missing (DK) parts of the name and/or address by referring to telephone directories or other appropriate sources available to you.
  - b. Complete 58c in a similar fashion. However, if there are more than two other hospitals/medical facilities, continue to record names and addresses in the notes space or on a separate sheet of paper, which you should include between pages 20 and 21 when you return the DFS-4 to your office.
  - c. If only one hospital or other medical facility is reported for question 58c, enter the information in the top block, and mark box 0 "None" in the bottom block.
2. Complete question 59 the same as instructed in 1. above for 58.
3. The Provider Permission Form can be signed only by the Sample Person him/herself. If you are interviewing a proxy, mark box 2 in Item P5b and end the interview.
  - a. If you are interviewing the Sample Person by telephone, personal visit, or even with an interpreter, ask question 60.
    - If the Sample Person is reluctant to grant permission, remind him/her of the confidential nature of all data collected, including that obtained from the medical records. Also, explain that this interview is only one part of the total survey: Abstractive information from medical records is another. To ensure the overall success of the survey, we need his/her permission to contact hospitals, doctors, and other medical facilities.



●If the Sample Person agrees, mark "Yes" in 60, prepare the Provider Permission Form, and present it to the Sampler Person as instructed in #4 below.

●If the Sample Person will not give permission, mark "No" in 60 and end the interview.

Note: Ending the interview with 58a, P5b, or 60 does not itself constitute a "partial" interview.

4. Before presenting or mailing the Provider Permission Form on page 23 to the Sample Person, CAREFULLY AND COMPLETELY transcribe the control information from the questionnaire label to the Provider Permission Form. (See page 6-1 for a description of the fields on the label).
  - a. For a personal visit interview, provide the DFS-4 opened to page 23 to the Sample Person. Since the form has to be signed in blue or black ink, allow the Sample Person to use one of your pens.
    - If the Sample Person cannot read the Permission form, read it to him/her and show where to sign. (If using an interpreter, ask the interpreter to read the form aloud in the appropriate language).
    - If the Sample Person has difficulty writing, enter his/her complete name in the body of the statement and enter the date at the bottom. The Sample Person still must sign his/her name (or make his/her mark).
  - b. For a telephone interview, explain that you will mail the Provider Permission Form to the Sample Person for signature and return. Ask that he/she sign the form immediately upon receipt and return it to the Regional Office in the postage paid envelope.
    - Carefully remove the Provider Permission Form from the DFS-4 and mail it along with a return envelope preaddressed to your Regional Office as soon as possible after the interview.
5. Complete the Call Record on page 1 as well as the Final Status information on page 2.

## **CHAPTER 11. POST-INTERVIEW TASKS**

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### **A. OVERVIEW**

After you have completed the DFS interview, thank the respondent and emphasize the importance of his or her contribution to the survey. You then must edit the questionnaires and mail them to your regional office.

### **B. EDITING THE DFS QUESTIONNAIRE**

Editing is the review of completed questionnaires to make sure they are filled completely, accurately, and clearly. This task is an integral part of the interviewing process.

Edit the DFS questionnaires as soon as possible after you have completed the interview. If you are able to do so, perform a quick edit of the questionnaire before terminating the phone call or leaving the respondent. If you discover that an item is missing or in need of clarification, try to get the necessary information from the respondent before you go. Perform the following more detailed edit later.

### **C. EDITING GUIDELINES**

Follow these general guidelines when editing:

- Make sure that all answers are legible;

Check your handwriting on all items, particularly verbatim responses and entries made in the "Notes" section. Be sure all check box entries are clear.

- Write out all abbreviations;

Make sure that you write out any abbreviations or short-hand entries you may have used during the interview. (NOTE: This does not apply to States, which always should be entered with their standard two-letter abbreviation.)

- Make sure that each applicable item is answered;

Check for questions that have not been answered. If an item is missing, call the respondent and attempt to obtain the missing information. If you are unable to get the information, you can note that it was "omitted in error", but under no circumstances should you try to enter the missing information from memory.

- Make sure you marked precoded answer boxes correctly;

Verify that you marked no more than one box if only one answer is expected.

- Check each item with skip instructions;

Check and make sure that questions have not been answered unnecessarily, or that relevant questions have not been skipped by mistake.

- Make sure that dates are filled correctly;

Check that all dates are entered with 2-digit numerals for month, day, and/or year.

- Explain any problems in the "Notes" sections;

You might add notes concerning the respondent, the interviewing situation, or anything else that might be helpful in interpreting the data.

- Check the cover page of each questionnaire;

Check that the required information is filled on the cover page of each questionnaire. In Part I, Call Record, make sure that your last entry refers to when the interview was conducted and/or the final status was determined.

Also, be sure to mark Part II, Status, with the appropriate information. Enter in Part III, New Address the address and phone number where the sample person currently resides if different from that on the label.

#### **D. TRANSMITTING COMPLETED WORK TO THE REGIONAL OFFICE**

After you edit the questionnaires, send the completed materials to your regional office on a flow basis. Do not hold completed questionnaires until the end of the Wave. Mail them to your RO as soon as they are completed.

- If you have a DFS-4 and DFS-1/2/3 for the same sample person, place the DFS-4 inside the other questionnaire when transmitting them back to the RO.
- If you filled a DFS-2 for an emancipated youth, place the DFS-2 inside the original DFS-1 when transmitting them back to the RO.

#### **E. COMPLETING YOUR ASSIGNMENT**

Be sure to complete your assignment by the deadline indicated by your regional office. If you foresee problems meeting this deadline, contact your supervisor immediately.

## **CHAPTER 12. INTERVIEWING PERSONS WITH DISABILITIES**

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### **A. INTRODUCTION**

With the exception of some elderly persons, virtually all Sample Persons and Sample Children have disabilities. It is especially important that you are comfortable enough with the situation to be able to collect good data, and that respondents are comfortable enough to provide good information.

Our culture's frequent emphasis on youth, good looks, athleticism, and so forth, may sometimes make it seem that disabilities are "unusual" or "abnormal". Do not let such a notion influence you into treating a Sample Person as an object of pity, an incompetent, or something to be afraid of. You may feel more comfortable if you think of family or friends who have disabilities. This shouldn't be too hard to do since there are about 43 million persons with disabilities in the United States, and chance are one in five that your own household has a person with disabilities.

It is vitally important to always think of each Sample Person firstly **AS A PERSON**, and only secondarily as a person with a disability.

### **B. GENERAL "TIPS"**

1. Always treat a person with a disability as a person; maintain eye contact with him/her.
2. Do not make assumptions about a person's mental or physical capacities that could be unwarranted and insulting.
3. Be careful of the words you use in connection with disabilities, but do not become overly self-conscious about saying to a blind person, for example, "*I'm sure you see what I mean.*"
4. If your contact is with another household member, be clear that it is the adult Sample Person you need to see or talk to.
5. If a third party is involved as an interpreter or assistant to the Sample Person, always keep in mind who the actual Sample Person is and focus attention on him/her.
6. Try to free the room of other distractions, such as a noisy TV, active pets, or playing children. Suggest closing doors when it will help ensure privacy and/or cut down on background noise.
7. Allow the respondent to interrupt the interview at any time with questions or comments about the survey, but as with any other survey, tactfully keep the interview flowing.

8. Repeat questions or answer categories as necessary, without a condescending tone. Take notice of the respondent's demeanor and expressions. If he/she appears confused, offer to repeat the question and/or answer categories. Refer to Chapters 7-11, as appropriate in this manual if you need to explain the meaning of a question or answer.
9. Be sure to give positive reinforcement to appropriate responses without appearing to pass judgement on the content of the response.
10. If a Sample Person appears extremely fatigued, offer to temporarily suspend the interview. This may be a short "time-out", a few minutes break, or simply a "little chat". Make arrangements to complete the interview at another time only if the Sample Person needs more than a short, temporary break.
11. Allow yourself and the respondent the time needed to conduct a good interview. Make arrangements to complete the interview at another time if this is the best way to acquire valid and reliable data. Do not rush the interview.
12. Reserve some of these same rights for yourself -- ask for a clarification if a response is not clear to you, request a "time-out" if you need to collect your thoughts, and so forth.

### **C. DISABILITY-SPECIFIC "TIPS"**

#### **1. Mental Disabilities**

Mental retardation and mental illness are subjects we may prefer to ignore, but these disabilities are fairly common and may account for a number of Sample Children and adult Sample Persons in your DFS assignment.

MENTAL ILLNESS - Also known as emotional or psychiatric disabilities.

Some forms of mental illness may not enter into the interview situation at all, while others may make it impossible for the Sample Person to respond with or without assistance from a third party. Virtually all Sample Persons with mental illness who you will interview, control the illness through some combination of medication, professional therapy, and support groups. Also, many forms of mental illness will have no effect whatsoever on the Sample Person's ability to respond to the interview.

The following are some more tips to make both you and the respondent feel more comfortable:

- ◆ Make sure that you are always positive and personable, but business like.
- ◆ Some Sample Persons (or proxy respondents) may want to vocalize feelings that arise in reaction to particular questions. Tolerate such expressions of feelings, but clearly let respondents know that they did not answer the question. Try to redirect the respondent by distinguishing between thoughts (which in most cases you record on the questionnaire as "answers") and feelings.

- ◆ If a respondent's thoughts or attention wander from the interview, try to get him/her back on track with a reminder if the specific reason for your visit.
- ◆ Gently refrain from answering any personal questions the respondent might direct to you, humorously reminding him/her that asking the questions and recording the responses is your job.

## MENTAL RETARDATION

There are gradations of mental retardation. If when you ask to interview the adult Sample Person you are told that he/she is mentally retarded, discuss with the respondent the possibility of the Sample Person still taking part in the interview, with or without assistance by a third party. Use a proxy respondent only if necessary.

The following are some tips that may assist you:

- ◆ Keep the interview focused on the Sample Person rather than the assistant or proxy. If the adult Sample Person is responding with assistance, keep eye contact with the Sample Person. Act as much as possible as if the assistant is invisible.
- ◆ Be alert to cues that the assistant is "taking over", such as responding to questions before the Sample Person can react. Refocus the interview on the Sample Person by not recording responses until the Sample person gives them or by repeating the question directly to the Sample Person (again as if the assistant is invisible).
- ◆ With the first set of questions, try to evaluate the Sample Person's ability to respond in this survey, so you can determine early on if you must use a proxy respondent for the interview. Even if a proxy is required, keep the Sample Person present for the duration of the interview, asking him/her to verify responses from time to time and instructing him/her to speak up if the proxy gets something wrong.
- ◆ Be aware that hypothetical situations may be taken very literally by the Sample Person. For example, when you ask if he/she "would be able to work if ...", you may get responses about the actual current abilities.

## LEARNING DISABILITY

There are a variety of disorders in mental processes that can appear as difficulties with particular functions, like reading, spelling, writing, or paying attention, while having little or no effect on the person's other mental abilities and functions. For a Sample Person with a learning disability, review the General "Tips" in Section B of this chapter.

### 2. Sensory Disabilities

Hearing, sight, and speech disabilities vary in their degree. Do not assume dark glasses, a white cane, or a guide dog necessarily imply a complete loss of vision any more than a hearing aid means complete deafness.

Interviews with adult Sample Persons with sensory disabilities probably will take extra time and may even require a second visit to complete. Regardless of the situation, do not rush the interview.

#### BLINDNESS/LIMITED VISION

A "legally blind" person may have some residual sight. The following are some tips that may help you with Sample Persons having vision disabilities:

- ◆ Unless the Sample Person is totally blind, try to place yourself under a good light source, so that the Sample Person can have the best opportunity to visualize you.
- ◆ If the Sample Person has a guide dog, you may ask permission to pet it briefly. This establishes your friendship with both the Sample Person and the dog. However, do not continue to show attention to the dog, as to do so might interfere with the dog's functioning to assist its owner.
- ◆ As with a telephone respondent, a blind respondent will benefit from a brief description of the DFS materials you use and a running commentary on what you are doing. For example, *"Now it will take me a moment to check some previous answers and determine which question to ask next."*
- ◆ Hand the flashcard to the partially sighted respondent, so he/she can hold it at the right distance or in the proper light to read it most comfortably. Ask if the card and its categories are clear, and offer to read the card if necessary.
- ◆ When reading answer categories, offer to repeat the categories on request.

#### DEAF/HARD OF HEARING

Persons born deaf or deafened before learning to speak, often use American Sign Language (ASL) to communicate. There are other forms of sign language also used for communications. Because of the differences, another household member probably is the best choice for a sign language interpreter. However, if you must go outside the household for a sign language interpreter, make sure to match the needs of the Sample Person with the capabilities of the interpreter.

Sample Persons who have been totally or almost totally deaf for a long time, may exhibit some degree of speech difficulty because they do not receive auditory feedback on how they sound. Be sure to review the section below on Speech Difficulty as well.

Sample Persons with adult-onset hearing loss may be reluctant to admit it, or to admit the full extent of the loss. Often, such a person will have someone like a spouse or other family member sit alongside and relay your questions into the "better ear". Treat this as an assisted interview and focus your attention on the Sample Person, directing all questions to him/her not the assistant.

The following are some specific tips for interviewing a Sample Person who is deaf or hard of hearing:

- ◆ Maintain eye contact with the Sample Person, not the assistant or interpreter. Think of the assistant or interpreter as being invisible.
- ◆ Be sure to sit in full light so your face can be seen easily. Enunciate properly and do not chew gum, smoke, or suck a lozenge during the interview.
- ◆ Suppress the tendency to shout, as excess volume may actually interfere with comprehension. Clear enunciation is usually more important than volume, but do not use grossly exaggerated lip movements.
- ◆ Try to eliminate any background noises by asking if a TV or radio can be turned off or doors shut.
- ◆ Do not compromise the quality of the interview and the data you are collecting by rewording questions in a misguided effort to make them more understandable. Keep in mind that hearing loss does not necessarily affect mental acuity.
- ◆ Do not be afraid to repeat a question or ask for clarification of a response.
- ◆ Do not rush the interview.

#### SPEECH DIFFICULTY

Stuttering is probably the most common speech difficulty which you will encounter. The respondent cannot control the problem, and you need to be patient: do not rush the person (which would only contribute to the problem) and avoid especially the tendency to try to complete the response for him/her. When a stutter occurs at the end of a response, do not talk over him/her by asking your next question. Wait until the respondent is finished before asking the next question.

Other conditions that may interfere with your understanding of the Sample Person's speech include the effect of a stroke; paralysis of the soft palate, lips, and/or tongue; injury, disease, or surgical removal of the voice box; and congenital disorders, such as a harelip, cleft palate, and so forth. Whatever the cause, the following tips should be useful for interviewing a person with a speech difficulty:

- ◆ Do not rush the interview.
- ◆ Try to place yourself where you can best see and hear the respondent.
- ◆ Carefully avoid the tendency to try to speak more distinctly and loudly yourself -- this has no affect on the respondent's ability to speak.



- ◆ Do not compromise the quality of the interview and the data you are collecting by rewording questions in the misguided effort to simplify the responses to them. Keep in mind that a speech problem does not indicate diminished mental acuity.
- ◆ Above all, do not pretend you understand a response if you really do not. This can not only result in recording incorrect information, but could prove embarrassing later in the interview if it causes you to ask inappropriate questions. If necessary, say something like, *"This information is so important that I want to be sure I completely understand your answer. Will you please say it again, perhaps in a slightly different way?"*

### 3. Mobility Disabilities

As with other physical disabilities, guard against assuming a connection between bodily functions and mental facilities.

In addition to the General "Tips" in Section B of this chapter, the following are some important reminders for interviewing persons with mobility disabilities.

- ◆ Unless you find out differently, assume the Sample Person has an active mind.
- ◆ Avoid voyeuristic staring at bodily anomalies, disfigurements, missing limbs, and unusual equipment.
- ◆ Do not ask personal (i.e., not in the questionnaire) questions about the exact nature of the disability, related difficulties, lifestyle implications, or particular circumstances. There is an all-too-human tendency to assume a degree of intimacy that really does not exist.
- ◆ Offer help or assistance as you feel appropriate, but do not jump to do something for the Sample Person without first asking permission. Offer help by asking, *"May I help you?"* If the person answers affirmatively, then ask, *"How?"* In this way, you avoid doing something the person would prefer to do him/herself.
- ◆ Do not ask the Sample Person's assistant to assist you.

### 4. Other Disabilities

There are certain other specific disabilities that are unlikely to appear in your DFS assignments, but merit a brief discussion because of the special challenges they may pose if encountered.

#### AIDS/HIV INFECTION

Although not specifically screened for in the original HIS Disability Supplement interview, you may still have in your assignment a person who has AIDS or who tested positive for the HIV infection. If so, simply treat him/her as you would any other Sample Person.

The most important thing you must realize is that the HIS virus is transmitted only through the interchange of bodily fluids such as blood, urine, semen, etc.. You cannot contact HIV through the air, simply by being in the same room with an infect person, by casual contact (such as touching someone's arm), or even by sharing a drinking glass.

#### TOURETTE'S DISEASE/SYNDROME

This is a rare disorder in which the person has nervous tics, involuntary movements, and/or vocalizations over which he/she has no control. These involuntary actions may include: facial twitches or grimaces; sudden jabbing of a fist or kicking; repeating a word or phrase just spoken by someone else; or the often sudden and explosive uttering of vulgar, obscene, or otherwise inappropriate words. This condition can cause great distress for the person who cannot control these unwanted movements and/or vocal outbursts. Although it may seem more menacing, like stuttering this condition cannot be controlled and may actually be aggravated by efforts to contain them or a feeling of being rushed.

A person who has lived with Tourette's knows that it is best to forewarn new contacts. If you are advised of this situation, ask how best you can help if the Sample Person exhibits the symptoms during the interview. However, whether or not you are forewarned, you can be helpful by ignoring the outbursts and focusing on the actual responses the Sample Person is trying to give you. Don't become flustered if your own words are repeated involuntarily and rush the interview. Encourage the respondent to express his/her thoughts completely, accepting a longer answer than you need to record.

#### OTHER

If you encounter a Sample Person with a disability that is unfamiliar to you and not covered in this chapter, discuss it with your supervisor to determine if there are *any* special considerations that you might need to make to complete the DFS interview.

#### D. INSTITUTIONALIZED PERSONS

Although all Sample Persons were "noninstitutionalized" at the time of the original HIS interview, some may have entered hospitals, nursing homes, convalescent homes, sanitariums, or similar institutions since then. If through the screening questions on page 2 of the DFS-2 or DFS-3 questionnaire you determine that you should interview the Sample Person at the institution follow these general guidelines:

1. Telephone the institution, introduce yourself, and ask if there are any special procedures you need to follow (such as coming only during specific hours, reporting first to a specific staff member, and the like).
2. Be sure to fully comply with any special procedures when you visit the institution.
3. Try to arrange for as private a setting as possible to interview the Sample Person. If total privacy is not possible, have the Sample Person agree to the presence of others prior to beginning the interview. Make arrangements to return at another time if a more ideal situation would be available then.

4. If the institution will not permit you to interview the Sample Person, or if you begin the interview and determine that the Sample Person is physically or mentally unable to respond, recontact your original respondent and complete the rest of the screening questions to identify a knowledgeable proxy respondent.
5. Interview a Sample Person in an institution the same as you would one not in an institution. There are a few items in the questionnaires that are skipped for an institutionalized Sample Person, but otherwise, there are no differences in the interviews.