

finding common ground in the era of welfare reform



interviewing manual

a study of the impact of
welfare reform on the health of
chronically ill children and their mothers

New York, NY
2001

finding common ground

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**A Study of the Impact of Welfare Reform on the Health of
Chronically Ill Children and their Mothers**

INTERVIEWING MANUAL

New York City

2001

Last updated: 8/16/01

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PROJECT DESCRIPTION

BACKGROUND

The goal of this study, entitled *The Impact of Welfare Reform on the Health of Chronically Ill Children and their Mothers*, is to explore the experiences of families who may or may not be receiving Temporary Assistance for Needy Families (TANF or welfare) with children with chronic illnesses. Specifically, we seek to: 1) examine the experience of chronically ill children and their mothers with TANF and health insurance; 2) evaluate the association between *TANF status*, *health status*, and *health care utilization*; 3) evaluate the association between *health insurance status*, *health status*, and *health care utilization*; 4) evaluate the association between *TANF status* and *health insurance status*; and 5) evaluate the impact of both *child* and *maternal illness* and *TANF status* on *maternal employment*. We are also interested in identifying factors that influence health care utilization for chronically ill children and their mothers, including potential barriers to the use of preventive medications and adherence to outpatient management plans.

This is a longitudinal cohort study with two rounds of data collection – in-person baseline surveys and follow-up telephone surveys at 6 months. Trained interviewers will approach mothers or primary caretakers of children at one of 3 general sites: the Pediatric Neurology Clinic (Harkness Pavilion), the Ambulatory Care Network Centers (ACNC) (5 different locations), and the Children’s Hospital Inpatient Wards (floors 8, 10, and 11). Women (or the adult caregiver present) and their children will be eligible for the study if the following criteria are met: 1) child age 2-12 years; 2) child with a diagnosis of asthma, sickle cell anemia, hemophilia, diabetes, seizure disorder, cystic fibrosis, or serious neurologic impairment (such as cerebral palsy); 3) mother or primary caretaker available for interview; and 4) mother or primary caretaker able to complete interview in Spanish or English. After obtaining informed consent, the interviewers will administer the structured, pre-coded survey in either English or Spanish. Participants who complete the interview will be given a \$10 gift, as well as referral information regarding community social and health services.

Data will be collected on the following dependent variables: child and maternal health status, including maternal mental health status; child and maternal health care utilization; health insurance status; welfare status and maternal work experiences. Pertinent demographic information will also be collected. Study participants will be divided into three comparison groups for analysis based on their TANF status at the time of the initial interview: current TANF recipients, former TANF recipients, and those have never received TANF.

The ultimate goal of this study is to identify needs of poor families with chronically ill children. We will then provide this information to health care providers, researchers, community advocates, and policymakers.

RECRUITMENT SITE LOGISTICS

CONTACTS

1. Site Coordinator:

Barbara Pastrana, MD
Center for Population and Family Health
Mailman School of Public Health, Columbia University
60 Haven Avenue, B-2 room 209
New York, NY 10032
Phone: (212) 304-5293
Fax: (212) 304-5609
Email: bap2001@columbia.edu

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Center for Population and Family Health
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New York, NY 10032
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3. Co-Principal Investigators:

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Wendy Chavkin MD, MPH
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Chair (Interim), Center for Population and Family Health
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New York, NY 10032
Phone: (212) 304-5220
Fax: (212) 304-5609
Email: wc9@columbia.edu

RECRUITMENT SITES

1. Ambulatory Care Network Centers

Medical Director: Mary McCord

?? 21 Audubon Practice

21 Audubon Avenue (166th Street and Audubon Avenue)
New York, NY 10032

Phone: (212) 342-3200 (patient representatives)
(212) 342-3218 (nurses station)

Fax: (212) 342-4733 (upstairs)
(212) 342-4734 (administrative office-downstairs)

Office/nurse manager: Bernadatte Miles, NCC (212) 342-3220

Administrative Assistant's Office: (212) 342-4701

?? Broadway Practice

4781 Broadway (202nd St)

New York, NY 10034

Phone: (212) 304-6922

Fax: (212) 304-6925

Office/nurse manager: Michelle Lewis, Practice Manager (212) 304-6928

?? Morgan Place

610 West 158th Street

New York, NY 10032

Phone: (212) 939-6007

(212) 939-6018 (back office)

Fax: (212) 939-6008

Office/nurse manager: Judy Aponte, RN (212) 342-3065

?? 180th Practice

549 West 180th Street

New York, NY

Phone: (212) 342-3060

Fax: (212) 928-3647

Office/nurse manager: Judy Aponte, RN (212) 342-3065

?? Charles B. Rangel Community Health Center

534 West 135th Street (Between Broadway and Amsterdam Avenue)

New York, NY 10031

Phone: (212) 491-2311

Fax: (212) 491-2323

Office/nurse manager: Annita Treacy, RN, NCC (212) 491-1299 (beeper)

2. Pediatric Neurology Clinic

181 Fort Washington Ave
Harkness Pavilion, Room 542
New York, NY 10032

Office/nurse manager: Lori Seidman, PNP (212) 305-4136

3. Children's Hospital Inpatient Wards

3959 Broadway
New York, NY 10032

?? **8th Floor South**

Office/nurse manager: Peggy Quinn (212) 305-5919

?? **10th Floor South**

Office/nurse manager: Lisa Springs (212) 305-7064

?? **11th Floor South**

Office/nurse manager: Maureen Rorke (212) 305-5946

SCHEDULES

SITE	MON	TUES	WED	THURS	FRI	SAT
ACNC 21 Audubon Practice	9a – 5p	9a – 5p	9a – 5p	9a – 5p	9a – 5p	X
ACNC Broadway Practice	9a – 5p	9a – 5p	9a – 5p	9a – 5p	9a – 5p	X
ACNC Morgan Place	9a – 5p	9a – 5p	9a – 5p	9a – 5p	9a – 5p	X
ACNC 180th Practice	9a – 5p	9a – 5p	9a – 5p	9a – 5p	9a – 5p	X
ACNC Charles B. Rangel Community Health Center	9a – 5p	9a – 5p	9a – 5p	9a – 5p	9a – 5p	X
Pediatric Neurology Clinic	X	12n – 6p	X	X	X	X
Children’s Hospital Inpatient Ward – 8th Floor South	Open 24hrs a day, but may find Rs present during evening or weekend hours.					
Children’s Hospital Inpatient Ward – 10th Floor South	Open 24hrs a day, but may find Rs present during evening or weekend hours.					
Children’s Hospital Inpatient Ward – 11th Floor South	Open 24hrs a day, but may find Rs present during evening or weekend hours.					

INTERVIEW PROCESS

GETTING STARTED

The interview is the most crucial part of the study. Every other part of the study hinges on whether we can recruit enough patients into the study and obtain valid, *unbiased* information from them. Below is information that should make it easier to identify and enroll study subjects.

Materials You Will Need At Every Shift

At the start of each interview shift, you will need to have the following items:

?? Interview manual

This manual will serve as your reference guide throughout the study period. Be sure to carry it with you during every interview shift.

?? Survey materials

Copies of the surveys, screening and consent forms, and tally sheets will be available from the site coordinator (60 Haven Ave, B-3).

?? Gift

Interviewers will provide each respondent who completes the interview with a gift card. The gift cards will be given to you by the site coordinator. They have cash value so interviewers must be sure to safeguard them. The site coordinator will keep track of amount and identification number of cards distributed to interviewers.

?? Resource materials

Interviewers will provide each respondent with an information sheet on social services available in the New York City area at the end of the interview.

Eligibility to Participate in the Survey

This study is aimed at interviewing mothers of children with chronic illnesses; therefore, most of the eligibility criteria refer to the child. The child must be:

?? age 2 – 12 years **AND**

?? must have one of the following diagnoses given by a physician:

- | | |
|---------------------------------------|--|
| - Asthma | - Cystic fibrosis |
| - Sickle cell anemia | - Serious neurological impairment (such as cerebral palsy) |
| - Hemophilia | |
| - Diabetes | |
| - Seizure disorder (such as epilepsy) | |

?? the mother or primary caretaker must be able to complete interview in Spanish or English

Only one child per family can be enrolled. Because we are trying to link the child's health to the parent's work and welfare experiences, we cannot enroll more than one child in a family—to do so would result in that parent's experience being counted twice.

CONDUCTING THE INTERVIEW

Identifying Potential Respondents

We will recruit respondents from three main sites: the ACNC clinics (5 locations), the inpatient pediatric wards (8th, 10th, and 11th floors) at the Children’s Hospital, and the Pediatric Neurology Clinic (Harkness Pavilion). The procedures for identifying potential enrollees will vary a little at each site.

?? ACNC Clinics

Upon arrival at the clinic, the interviewer should first “check-in” with the office/nurse manager to alert her/him that an interviewer is present in the clinic.

All mothers or primary caretakers who bring their child to the clinic for well-child and urgent care visits should be approached in the waiting area, given a brief introduction to the survey, and, if willing, screened for eligibility.

?? Pediatric Inpatient Wards

All children admitted to the hospital with one of the specified diagnoses for eligibility will be identified in one or more of the following ways: (1) approach head nurse for each floor for information concerning patients recently admitted who satisfy the eligibility criteria; (2) obtain list of recent admits from chief resident: and or (3) run hospital computer search by diagnostic category to identify eligible patients. After identifying patients who are eligible, the interviewer will approach the mothers or primary caregiver at the patient’s room and conduct these interviews in the room or another private area. Some of these interviews may be conducted over the phone, if, for example, consent is obtained in person but the child’s stay in the hospital makes it difficult to conduct the interview at that time. The interviewer must, however, set up an appointment to call the respondent (ideally) later that day and complete the interview. The gift would then be mailed to the respondent by the site coordinator.

?? Pediatric Neurology Clinic

All mothers or primary caretakers who bring their child to the clinic should be approached in the waiting area, given a brief introduction to the survey, and, if willing, screened for eligibility. Upon arrival at the office, however, the interviewer should first “check-in” with the office/nurse manager to alert her/him that an interviewer is present in the office.

Approaching the Family

The script at the beginning of the survey should guide your introduction so that everyone is approached in a similar manner to minimize bias. Below are guidelines for approaching a potential respondent.

- ?? Introduce yourself as working on a study of families of children with chronic illnesses based at the Children's Hospital.
- ?? Ask them if they would be willing to answer a few questions to find out if they are eligible to participate.
- ?? Describe the amount of time the survey is likely to take (approx. 30 min)
- ?? Reassure them that all the information is confidential and indicate the private area where the interview will be conducted (location information below); if in a crowded area, maybe moving to another, nearby location will provide more privacy.
- ?? Indicate that they may refuse to answer **any** questions
- ?? Indicate that a gift and information about social service will be provided to those who complete the survey

Screening for Eligibility

After you have approached respondents and explained the purpose of the study, you will need to ask them a few short questions from the "Screening Form" to see if they are eligible for the survey. If the respondent is eligible, it is then necessary to provide and review the Consent Form. Before asking the respondent any further questions, you must obtain her consent by having her sign two (2) consent forms: one copy is given to the respondent to keep for future reference, and one copy is given to the site coordinator with the completed screening form and survey.

If the parent agrees to the interview but does not meet the screening criteria, thank the parent for her willingness to participate and briefly explain why she is not eligible to participate.

If the parent declines to participate, you can try reassuring her that the information is completely confidential and that the survey will not interfere with the medical visit. If she still refuses, thank her for her time and note the reason for refusal on the screening form. In addition, this contact should be added to the Respondent Tally Sheet so that we can keep track of the number of families who were approached but declined to participate.

Location for the Interview

The location and timing for conducting the interview will depend on the site.

ACNC Clinics and Pediatric Neurology Clinic

At the start of your shift, check-in with the office nurse (manager) to let them know you will be interviewing patients that day. After conducting the screening in the waiting general area, try to take eligible patients to a more "private" location in the waiting room where the interview can be conducted a little more privately. Be sure to let the parent know that she will not miss her appointment by moving from the waiting area to a new location.

Pediatric Inpatient Wards

Based on the identification of potential enrollees from one of the various options mentioned earlier, interviewers will go to the patient's room and approach the parent or primary caregiver of the child. If the parent agrees to participate, the interview will be conducted in that patient's room or in a location convenient for the parent, such as a waiting area.

Responding to Interruptions in the Interview

How you respond to a request to stop the interview or to an interruption will depend on the respondent's reason for wanting or needing to leave:

- ?? If the parent wants to end the interview to tend to her child, you can reassure her that you can pick up the survey where you left off (when she is ready) and give her an estimate how much longer the survey will take to complete.
- ?? If the parent wishes to end the survey because it appears she is uncomfortable with a question, be sure to reassure her that all information is confidential. You may also tell her that she does not have to answer a question if she doesn't want to. Although it is important to get responses to every question, allowing the respondent to skip a question is preferable to ending the survey before its completed.
- ?? If the interview gets interrupted because the patient is called into a room or the doctor is ready to see the patient, tell the parent that since you have gotten so far you would really like to complete the survey when the medical visit is over. Give an estimate of how much more time it will take and obtain their primary contact information for the locating page located at the end of the survey. If the parent cannot stay past the visit, make arrangements to call the parent later that day and complete the survey over the phone. (Note: Gift cards will be mailed to the respondents, by the site coordinator, for surveys completed over the phone.)

Concluding the Interview

The most important thing to do after completing an interview is to thank the family for their time and patience. Let them know that you appreciate their sharing information about their experiences. Remember to give them the social services information materials and the gift card. Make sure that you have recorded at least two phone numbers on the Locating Page of the survey so that we may follow up in 6 months.

AFTER THE INTERVIEW

After you have finished interviewing the respondent, there are several things you will need to do to ensure that the responses on the survey instrument are accurate, complete, and *understandable*, and that your interviews are logged and accounted for.

Step 1: Finish filling out the cover sheet

After you finish interviewing the respondent, immediately check to make sure the following information on the survey cover is complete.

<ul style="list-style-type: none"> <i>/</i> Date / Interviewer initials / Medical record (MR)# (in-patient only) / Site / Language / Method 	<ul style="list-style-type: none"> <i>/</i> Diagnosis <i>/</i> Survey start, end, and total times <i>/</i> Complete via phone? <i>/</i> Survey complete? <i>/</i> Reason for incomplete survey
--	---

Do not fill in the Case #; this is assigned by the site coordinator.

Step 2: Fill in responses to skip pattern questions

At this time you will need to **carefully review** the survey and mark all the questions that were “skipped” as part of a skip pattern or that were not answered for other reasons. If a question was skipped as part of a skip pattern, it is coded INAP for “inapplicable;” if the respondent refused to answer a question, it is coded NR for “no response.” (The NR category is also used for questions the interviewer should have asked, but failed to do so. This should only be used after a telephone attempt to contact the respondent for the missing information has failed.)

Step 3: Turn in completed surveys to site coordinator

At the end of your interviewing shift, hand in all of your completed surveys, screening and consent forms to the site coordinator. If the coordinator is not at the 60 Haven Avenue office at the end of your shift, the surveys must remain in your possession until they can be left in her mailbox.

Step 4: Fill out the Respondent Tally Sheet.

In order to track the progress of the project, each interviewer will keep a log of his/her shift. It is very important to accurately record the following on the Tally Sheet:

- ~~/~~ Number of families interviewed
- ~~/~~ Number of families not eligible
- ~~/~~ Number of families refused
- ~~/~~ Total

INTERVIEWER CHECKLIST

?? **Before Interview Shift**

?? Make sure you have all the necessary materials

- Interview manual
- Screening forms and surveys
- Consent forms
- Gift cards
- Social services information sheet

?? Check-in with site coordinator (phone or in-person) at the beginning of each shift

?? **During Interview Shift**

?? Check-in at site (with office/nurse manager or supervisor, etc)

?? Identify semi-private area at site for conducting interviews

?? Start approaching potential respondents in the waiting areas or hospital rooms, and invite to participate in survey

?? Bring eligible respondents (one at a time) to private area and conduct interview

- Allow respondent to interrupt survey if called for medical appointment and make arrangements to continue survey when respondent returns

?? Upon completion of survey:

- Provide respondent with gift card
- Provide respondent with social services information sheet
- Remind respondent that someone will probably be calling her to follow-up in about six months
- Thank her for her time
- Edit survey instrument (i.e., fill in INAP responses, clarify marginal notes, etc) if no one else available to interview at that time. Otherwise, edit at the end of your shift, after all interviews have been completed.

?? **Following Interview Shift**

?? Ensure all completed interviews have been edited so there is no missing data

?? Call/leave message for site coordinator when shift is over to report number of surveys completed

?? Drop-off completed surveys to site coordinator

HOW TO ASK QUESTIONS

There are only a few types of questions present in this questionnaire. Once you familiarize yourself with them, you will be able to handle any question regardless of its specific content.

What follows is a discussion of these question types. Included are explanations and examples of the types of questions you will be working with. First, however, a word about three response categories (or possible answers to questions) that are used throughout the questionnaire.

COMMON RESPONSE CATEGORIES

In most questions, you will see the possible responses of:

- INAP.....inapplicable (-7)
- DK.....don't know (-8)
- NR.....non-response (-9)

All questions contain a DK and NR response, while INAP is included as a response only for questions that are part of a skip pattern. You'll learn more about skip patterns toward the end of this section.

Example:

- C1a. What type of health insurance is it?
- (1) Medicaid
 - (2) CHIP
 - (3) Private (through work)
 - (4) Private (purchased by individual)
 - (5) Other (Specify): _____
 - (-7) INAP
 - (-8) DK
 - (-9) NR

The first thing to remember about INAP, DK and NR, is that they are never read aloud to the respondent. (In fact, NEVER READ ALOUD ANYTHING WHICH APPEARS IN CAPITAL LETTERS.)

Second they are circled only according to the following conditions.

A. INAP: (inapplicable)

The code (-7) will be circled only when you did not ask a certain question of R (respondent) due to an instruction in the questionnaire to skip it. (See question type #7). For example, in question C1a above, if R had said previously that she DID NOT have health insurance you would not be asking her what type of insurance she had. You would have been instructed to skip QC1a because the question is "inapplicable," and (-7) would be circled after the interview was complete.

B. DK: (don't know)

The (-8) will be circled when a respondent, on her own, tells you that she does not know the answer to a question. Before excepting “don't know” as the final response you must probe, in an effort to get an answer. When a respondent initially replies “gee...I really don't know,” a PROBE on your part of

“that's ok—take a minute to think about it” or “well...what is your best guess”

often prompts her to reply. We want you to accept as few “don't know” responses as possible.

C. NR: (no response)

Code (-9) is circled in only two circumstances. The first is in the event that R refuses to answer a question. Although you should approach each question with the expectation that it will be answered, exceptions do arise. When a respondent does not want to answer a question, it is important to remind her that her answers are strictly confidential. After one such attempt to encourage a response, respondents should be treated courteously and graciously if they still refuse to answer a particular question—NR is circled—and you move on to the next item.

NR is also used in the (rare!) event that you, as the interviewer, forget to ask a question, or skip it by mistake. You will discover your error during the editing process. The first step should be to call the respondent as soon as possible, to obtain a response for the skipped question. If, after several attempts, you are unable to contact the respondent, then the item should be coded “NR.”

IMPORTANT: Note the difference between INAP and NR. INAP signifies an intended skip of a question—dictated by instruction in the questionnaire. NR is used when you forgot or skipped a question by mistake (or when respondent does not answer a question.

DIFFERENT TYPES OF QUESTIONS

QUESTION TYPE #1

Feature: Question ends in several dots.

Example: B6. In the *past year*, have you been to a doctor or clinic for any of the following: . . .

	<u>Yes</u>	<u>No</u>	<u>DK</u>	<u>NR</u>
(a) annual check-up (physical)?	(1)	(0)	(-8)	(-9)
(b) dental visit (cleaning/check-up)?	(1)	(0)	(-8)	(-9)
(c) general gyn visit (eg, pap test, family planning)?	(1)	(0)	(-8)	(-9)
(d) mammogram?	(1)	(0)	(-8)	(-9)
(e) eye check-up?	(1)	(0)	(-8)	(-9)
(f) counseling?	(1)	(0)	(-8)	(-9)

E3. With regard to Food Stamps, do you receive them . . .

- (1) solely for yourself,
- (2) solely for your child(ren),
- (3) for all of you, or
- (0) not at all?
- (-8) DK
- (-9) NR

Explanation: The general rule when reading aloud is to **READ TO THE PUNCTUATION MARK**. Dots at the end of a question indicated to you that you should **READ THE ANSWER CATEGORIES ALOUD**, until you get to the question mark. In a question that ends in dots (.....), the first letter of each answer category will not be capitalized. This serves as an extra reminder that they are part of the question, and that they should be read aloud. (INAP, DK, and NR should never be read aloud, as mentioned earlier).

QUESTION TYPE #2:

Feature: Question stem ends in a question mark or period (not dots....)

Example: E1. Does your family currently receive TANF (“welfare”)?

- (1) Yes [GO TO E1a]
- (0) No (includes recently applied) [SKIP TO E1b]
- (-8) DK
- (-9) NR

OR

C1a. What type of health insurance is it?

- (1) Medicaid
- (2) CHIP (or Child Health Plus)
- (3) Private (through work)
- (4) Private (purchased by individual)
- (5) Other (*Specify*): _____
- (-7) INAP
- (-8) DK
- (-9) NR

Explanation: The same rule of READ TO THE PUNCTUATION MARK applies here. Therefore, the answer categories in questions such as these ARE NOT READ ALOUD. You will note that the first letter of each category is capitalized as a further reminder that they are not part of the question to be read aloud.

In questions where you do not read the answer categories, you must listen very carefully to the response given, and then find and code the appropriate answer. At times you will need to PROBE for an appropriate response. For example, in C1a above, what if the respondent said:

“I have United Health Care.”

An appropriate probe would be,

“is that coverage through your employer or did you purchase it independently?”

UNLESS OTHERWISE STATED, you should only code one answer in questions such as C1a. If R cannot make up her mind, DO NOT CIRCLE TWO CODES. Probe until she chooses one over the others. There are a few exceptions to the “one code only” rule. See Question Type #3 for explanation.

QUESTION TYPE #3

Feature: Question has response columns titled Mentioned and Not-Mentioned.

Example: C4. Where do you *usually* go when [child’s name] is sick, or when you need advice about his/her health? [*Probe*: any other places?].

	<u>Mentioned</u>	<u>Not mentioned</u>	<u>DK</u>	<u>NR</u>
(a) Hospital clinic	(1)	(0)	(-8)	(-9)
(b) Private physician’s office	(1)	(0)	(-8)	(-9)
(c) Community health center	(1)	(0)	(-8)	(-9)
(d) Public health (Metrohealth) clinic	(1)	(0)	(-8)	(-9)
(e) HMO	(1)	(0)	(-8)	(-9)
(f) School nurse/clinic	(1)	(0)	(-8)	(-9)
(g) Pharmacist	(1)	(0)	(-8)	(-9)
(h) Herbalist	(1)	(0)	(-8)	(-9)
(i) Other	(1)	(0)	(-8)	(-9)
<i>Specify:</i> _____				

Explanation: It is acceptable in “Mentioned-Not Mentioned” questions to circle more than one “mentioned” code. In fact, it is your job to ask “what else” after R gives one of the responses above.

Therefore you can and often will have more than one “mentioned” response. The other answer possibilities (that R does not mention) will be coded “not mentioned” after the interview is completed. Like circling INAPs, this is part of the editing process. Each possible item needs to have one of the codes circled either “Mentioned” or “Not Mentioned.”

Remember because you read to the punctuation mark, the categories (private physician’s office, pharmacist, etc.) are NOT read aloud in the above example.

Notes: “Other (*Specify*)_____” appears occasionally in this questionnaire. This is to allow for the possibility that R may have a response that does not appear in the list provided. If this is the case, you will circle the number 1 next to “other” above, and WRITE IN exactly what R says. Please do not interpret what R says or write what you think R means. Write only what R says – exactly.

QUESTION TYPE #4

Feature: Question contains one or more phrases in brackets.

Example: C2b. Why does [child's name] no longer have health insurance?

Explanation: Parentheses at the beginning, end, or in the middle of a question indicate to you that **YOU ARE GOING TO HAVE TO INSERT A WORD** when you read to the respondent. In this case, you will insert the child's name:

“Why does Maria no longer have health insurance?”

QUESTION TYPE #5

Feature: The question contains no response categories, only open lines.

Example: G2. What happens with your child care arrangement when your child is sick?

(-7) INAP (-8) DK (-9) NR

Explanation: There are a few “open-ended” questions in this questionnaire. An open-ended question is one in which there are no pre-coded responses to circle, and your job is to write out exactly what the respondent says.

YOU MUST PROBE TO GET AS MUCH DETAIL ABOUT THIS TYPE OF QUESTION AS POSSIBLE. GOOD PROBES ARE:

?? Is your child still cared for in the same way, or is that not possible? How so?

?? Is there somewhere else you can take your child? Maybe a friend, or family member?

QUESTION TYPE #6

Feature: Answer categories contain skip patterns.

Example: E1. Does your family currently receive TANF (“welfare”)?

- (1) Yes [GO TO E1a]
- (0) No [SKIP TO E1b]
- (-8) DK
- (-9) NR

E1b. Do you not receive TANF because. . .

- (1) you don’t need it or never applied, [SKIP TO E2]
- (2) you applied, but were denied benefits, or [SKIP TO E2]
- (3) you used to receive it, but don’t now, or [SKIP TO E1e]
- (4) you recently applied and are waiting for a decision? [SKIP TO E2]
- (-7) INAP
- (-8) DK
- (-9) NR

Explanation: The instructions that you see in the answer categories (SKIP TO E1b) are called “skip instructions.” They appear frequently throughout this questionnaire. They are in ALL CAPITAL letters, which means that they are an instruction to you—in this case, an instruction about which question to ask next. You do not read them aloud.

IF NO SKIP INSTRUCTION APPEARS IN AN ANSWER CATEGORY, ALWAYS PROCEED TO THE NEXT QUESTION IN THE SEQUENCE.

Important note: The majority of questions in this questionnaire contain skip patterns. There are often very different skips associated with each possible response. Be careful! Remember, if there is NO skip pattern next to a particular response, you automatically go to the next question.

QUESTION TYPE #7

Feature: Question contains dots in the middle of the sentence

Example: G3. Has your child's health problem made it . . . to find child care when you need it?

- (1) harder,
- (2) easier, or
- (3) made no difference
- (-8) DK
- (-9) NR

Explanation: Dots in the middle of this question signal that you are to read the available responses as part of the sentence. For example, the above question would be read as, "Has your child's health problem made it harder, easier, or made no difference to find child care when you need it?"

STANDARD PROBES

As will be stressed throughout the interviewer training session, you must follow the wording of the questionnaire EXACTLY. You cannot add your own explanation or interpretation of the question without jeopardizing the standardized nature of the survey. This may be a different approach than you have used before, but it is ABSOLUTELY ESSENTIAL to the successful completion of this survey.

Some questions will contain specific probes for you to use, in which case, you should read them exactly as written. Below are some standard “probing” techniques, or responses for you to give when a respondent does not answer or understand a question as it appears in the questionnaire and there is no specific probe included for you in the question.

1. When R says “I don’t know” in response to a given question:

Standard probe: “that’s OK...take a minute to think about it.”

OR

“give me your best guess”

2. When R gives more than one answer to a given question:

Standard probe: “would you say it’s closer to ____ or _____?”

OR

“if you had to pick one, which one would you choose?”

3. When R doesn’t give you enough information on an open-ended question:

“can you tell me more about that?”

OR

“what is your back up plan when your child is sick?”

4. When R’s response doesn’t really answer the question:

Here you must respond to what the respondent told you. (“Yes...I see”) but then you must REPEAT THE QUESTION AGAIN EXACTLY AS IT APPEARS IN THE QUESTIONNAIRE. DO NOT TRY TO INTERPRET THE QUESTION FOR R.

5. If R wants you to give her a definition of a word:

(Ex: “Full-time” work or “TANF”)

You may do so IF ONE APPEARS IN THE QUESTION BY QUESTION SPECIFICATIONS. Otherwise, you must ask R to answer with whatever the question or work means to her. If she has no idea, take a DK response.

QUESTION –BY QUESTION

CASE# _____

MR# _____
(INPATIENT ONLY)

QUESTION - BY QUESTION

**WELFARE REFORM AND THE HEALTH OF CHRONICALLY ILL CHILDREN AND THEIR MOTHERS
(NYC)**

Date: ___/___/___ **Interviewer:** _____
(Mo) (Dy) (Yr) (initials)

Site: (1) ACNC
(a) Audubon Practice
(b) Broadway Practice
(c) Morgan Place
(d) 180th Practice
(e) Rangel Community Health Center

Diagnosis: (1) asthma
(2) sickle cell anemia
(3) hemophilia
(4) diabetes
(5) seizure disorder
(6) cystic fibrosis
(7) CP/serious neurological impairment

(2) Pediatric Neurology Clinic

Start time: _____

(3) Children's Hospital Inpatient Wards
(a) 8th Floor South
(b) 10th Floor South
(c) 11th Floor South

End time: _____

Total time: _____ minutes

Language: (1) English (2) Spanish

Needed to complete survey via phone?
(1) Yes (2) No

Method: (1) In person (2) Telephone (3) Both

Survey completed? (1) Yes (2) No

Reason for Incomplete Survey:

(1) Called in to see doctor
(2) Parent refused to finish
(3) Child too sick/needed attention
(4) Other (Specify):

Clinical Survey

Okay, so now we're going to start the survey.

We'll start with some general questions about your child's health.

[CHILD HEALTH]

A

A1. You've told me that your child has [insert diagnosis obtained during screening]. Does this health problem(s) ever make it difficult for [child's name] to take part in kids' activities like sports, gym class, playing outside, etc.?

We want to know if their illness limits their ability in any way

- (1) Yes
- (0) No
- (-7) INAP
- (-8) DK
- (-9) NR

A2. In the past 6 months, how many times has [child's name] been to a hospital *emergency room* (that is, since [month])?

- (1) None [SKIP TO A3]
- (2) Once
- (3) Twice
- (4) Three times
- (5) Four or more times ((SPECIFY) # _____)
- (-8) DK
- (-9) NR

calendar

Count back six months prior to the month of this interview on the calendar to help R with recall

A2a. What for?

(-7) INAP (-8) DK (-9) NR

A3. In the past 6 months, how many times has [child's name] been admitted overnight to the *hospital* (that is, since [month])?

- (1) None [SKIP TO A4]
- (2) Once
- (3) Twice
- (4) Three times
- (5) Four or more times (SPECIFY # _____)
- (-8) DK
- (-9) NR

calendar

A3a. What for?

(-7) INAP (-8) DK (-9) NR

A4. Does your child currently go to school or day care?

If child is in school, but is currently on vacation, mark YES.

- (1) Yes
- (0) No [SKIP TO A5]
- (-8) DK
- (-9) NR

A4a. During the past 6 months, about how many days did [child's name] *not* attend because of illness or injury?

___ ___ ___ days [ENTER 000, IF NONE]

calendar

- (-7) INAP
- (-8) DK [*PROBE*: Can you *estimate* a number using the calendar?]
- (-9) NR

A5. During the past 6 months, did your child miss a doctor or health appointment because you couldn't miss work or school?

- (1) Yes
- (0) No [*PROBE*: confirm R is attending school or outside work]
- (2) Not currently attending school or working outside the home
- (-8) DK
- (-9) NR

A6. Is your child supposed to take any medications prescribed by a doctor on a regular basis?

By regular basis, we mean medications that are taken every day—or are part of a regular regimen to control the child's illness, including inhalers for asthma that may be taken only upon an attack.

- (1) Yes [GO TO A6a]
What kind: _____
- (0) No [SKIP TO next section B1]
- (-8) DK
- (-9) NR

List all the medications. Try to get brand name, but if R does not recall, get a description. Example: Azmacort is an inhaler used regularly to prevent asthmatic attacks. If R does not know Azmacort but says inhaler, record "inhaler."

A6a. In the past 6 months. . .

If R says she sometimes has to skip dosages, mark 2.

- (1) have you given this medicine to your child regularly (ie, in the way the doctor prescribed it), [SKIP TO next section B1]
- (2) have you given it less regularly (ie, less frequently or smaller doses), or
- (3) did you not give the medicine to your child?
- (-7) INAP
- (-8) DK
- (-9) NR

A6b. Why did you give it less regularly or not at all? [*PROBE*: Any other reason?]

Mark as many responses as R mentions.

	<u>Mention</u>	<u>Not mentioned</u>	<u>INAP</u>	<u>DK</u>	<u>NR</u>
(a) Can't afford	(1)	(0)	(-7)	(-8)	(-9)
(b) No insurance	(1)	(0)	(-7)	(-8)	(-9)
(c) Insurance doesn't cover	(1)	(0)	(-7)	(-8)	(-9)
(d) Couldn't get to doctor's office	(1)	(0)	(-7)	(-8)	(-9)
(e) Couldn't get to pharmacy to refill	(1)	(0)	(-7)	(-8)	(-9)
(f) Wanted medicine to last longer	(1)	(0)	(-7)	(-8)	(-9)
(g) Couldn't get off from work	(1)	(0)	(-7)	(-8)	(-9)
(h) Lack of transportation	(1)	(0)	(-7)	(-8)	(-9)
(i) Language problems (eg, prescription in different language, couldn't follow the directions)	(1)	(0)	(-7)	(-8)	(-9)
(j) Other (<i>SPECIFY</i>): _____	(1)	(0)	(-7)	(-8)	(-9)

B1. First can you tell me if...

*[do not ask men]

	(A) <u>you routinely suffer from...</u>	(B) <u>Have you sought medical care in the last 6 months for this medical condition?</u>
	<u>Yes</u>	<u>No</u> <u>DK</u> <u>NR</u>
a. asthma/respiratory problems?	(1) [GO TO B]	(0) (-8) (-9)
b. diabetes?	(1) [GO TO B]	(0) (-8) (-9)
c. heart/circulatory problems? (high blood pressure, heart disease, heart murmur, palpitations, irregular heart beats)	(1) [GO TO B]	(0) (-8) (-9)
d. headaches/migraines?	(1) [GO TO B]	(0) (-8) (-9)
e. epilepsy/seizures/convulsions?	(1) [GO TO B]	(0) (-8) (-9)
f. depression?	(1) [GO TO B]	(0) (-8) (-9)
g. bone/muscle problems? (arthritis, numbness in legs/arms, lower back/neck/shoulder pain)	(1) [GO TO B]	(0) (-8) (-9)
h. *gynecological problems? (severe cramps, endometriosis)	(1) [GO TO B]	(0) (-8) (-9)
i. digestive/stomach problems? (ulcers, colitis, vomiting, persistent diarrhea, heartburn)	(1) [GO TO B]	(0) (-8) (-9)

This question reads as follows:
 "First can you tell me if you
 routinely suffer from
 asthma/respiratory problems?" If R
 says yes to QA, then ask QB "Have
 you sought medical care in the last 6
 months for this medical condition?"
 If R says no to QA, go on to the next
 item under A: "Do you routinely
 suffer from diabetes?"
 Continue in this manner to the end of
 the list.

[INTERVIEWER: IF R ANSWERED "YES" TO ANY QUESTION, GO TO B1AAA; IF R ANSWERED "NO" TO ALL QUESTIONS, SKIP TO B2.]

B1aaa. Does/do these/this health problem(s) ever make it difficult for you to take part in usual activities like working, driving, general housekeeping, etc?

- (1) Yes
- (0) No
- (-7) INAP
- (-8) DK
- (-9) NR

↓

We want to know if their illness
limits their ability in any way

B1bbb. In the last six months, have you missed school or work because of this health problem?

calendar

- (1) Yes
- (0) No [PROBE: confirm R is attending school or work] [SKIP TO B2]
- (2) Not currently attending school or working outside the home [SKIP TO B2]
- (-7) INAP
- (-8) DK
- (-9) NR

B1ccc. How many days in the last 6 months?

- ____ days
- (-7) INAP
 - (-8) DK
 - (-9) NR

Record days in three digits,
so if R says 8 days, mark it
as "008"

B2. In the past 6 months, how many times have *you* been to a hospital *emergency room* (that is since [month])?

calendar

- (1) None [SKIP TO B3]
- (2) Once
- (3) Twice
- (4) Three times
- (5) Four or more times (*SPECIFY #* _____)
- (-8) DK
- (-9) NR

B2a. What for?

- (-7) INAP (-8) DK (-9) NR

calendar

B3. In the past 6 months, how many times have *you* been admitted overnight to the *hospital*?

- (1) None [SKIP TO B4]
- (2) Once
- (3) Twice
- (4) Three times
- (5) Four or more times (*SPECIFY #* _____)
- (-8) DK
- (-9) NR

B3a. What for?

- (-7) INAP (-8) DK (-9) NR

B4. During the past 6 months, did *you* miss a doctor or health appointment because you couldn't miss work or school?

- (1) Yes
- (0) No [*PROBE:* confirm R is attending school or outside work]
- (2) Not currently attending school or working outside the home
- (-8) DK
- (-9) NR

B5. Are *you* supposed to take any medications prescribed by a doctor on a regular basis?

- (1) Yes [GO TO B5a]
What kind: _____
- (0) No [GO TO B6]
- (-8) DK
- (-9) NR

Same as questions in A6 sequence.

B5a. In the past 6 months. . .

- (1) have you taken this medicine regularly (ie, in the way the doctor prescribed it), [SKIP TO B6]
- (2) have you taken it less regularly (ie, less frequently or smaller doses), or
- (3) did you not take the medicine?
- (-7) INAP
- (-8) DK
- (-9) NR

B5b. Why did you take it less regularly or not at all? [*PROBE*: Any other reason?]

	<u>Mention</u>	<u>Not mentioned</u>	<u>INAP</u>	<u>DK</u>	<u>NR</u>
(a) Can't afford	(1)	(0)	(-7)	(-8)	(-9)
(b) Didn't have insurance	(1)	(0)	(-7)	(-8)	(-9)
(c) Insurance doesn't cover	(1)	(0)	(-7)	(-8)	(-9)
(d) Couldn't get to doctor's office	(1)	(0)	(-7)	(-8)	(-9)
(e) Couldn't get to pharmacy to refill	(1)	(0)	(-7)	(-8)	(-9)
(f) Couldn't get off from work	(1)	(0)	(-7)	(-8)	(-9)
(g) Lack of transportation	(1)	(0)	(-7)	(-8)	(-9)
(k) Language problems (eg, prescription in different language, couldn't follow the directions)	(1)	(0)	(-7)	(-8)	(-9)
(h) Other	(1)	(0)	(-7)	(-8)	(-9)

(SPECIFY): _____

B6. In the *past year*, have you been to a doctor or clinic for any of the following: . . . [**don't ask men*]

Read and record a response for each item. If R is male, skip (c) and (d) and mark INAP.

	<u>Yes</u>	<u>No</u>	<u>DK</u>	<u>NR</u>	<u>INAP</u>
(a) annual check-up (physical)?	(1)	(0)	(-8)	(-9)	
(b) dental visit (cleaning/check-up)?	(1)	(0)	(-8)	(-9)	
(c) *general gyn visit (eg, pap test, family planning)?	(1)	(0)	(-8)	(-9)	(-7) (male)
(d) *mammogram?	(1)	(0)	(-8)	(-9)	(-7) respondent)
(e) eye check-up?	(1)	(0)	(-8)	(-9)	
(f) counseling?	(1)	(0)	(-8)	(-9)	

[INTERVIEWER: IF RESPONDENT IS MALE, SKIP TO C1].

B7. Have you had a baby in the past year?

- (1) Yes
- (0) No [SKIP TO C1]
- (-7) INAP
- (-8) DK
- (-9) NR

B7a. Did you receive prenatal care during your pregnancy?

- (1) Yes
- (0) No
- (-7) INAP
- (-8) DK
- (-9) NR

Now I am going to ask you questions about your child's health insurance.

[CHILD INSURANCE]

C

C1. Does [child's name] have health insurance *now* (such as Medicaid, CHIP or private insurance)?

- (1) Yes
- (0) No [SKIP TO C1c]
- (-8) DK
- (-9) NR

C1a. What type of health insurance is it?



Use the list on the right to identify the correct type of insurance coverage if R provides you with the program name.

- (1) Medicaid
- (2) CHIP (i.e., Child Health Plus)
- (3) Private (through work)
- (4) Private (purchased by individual)
- (5) Other (*SPECIFY*): _____
- (-7) INAP
- (-8) DK
- (-9) NR

C1b. Was there any time in the *past year* that [child's name] did not have health insurance?

- (1) Yes [SKIP TO C2a]
- (0) No [SKIP TO C4]
- (-7) INAP
- (-8) DK
- (-9) NR

C1c. Did [child's name] have health insurance at any time in the *past year*?

- (1) Yes [SKIP TO C2b]
- (0) No [SKIP TO C3]
- (-7) INAP
- (-8) DK
- (-9) NR

C2a. Why did you not have health insurance for [child's name] during that time?

	<u>Mention</u>	<u>Not mentioned</u>	<u>INAP</u>	<u>DK</u>	<u>NR</u>
(a) Can't afford it	(1)	(0)	(-7)	(-8)	(-9)
(b) Job doesn't provide	(1)	(0)	(-7)	(-8)	(-9)
(c) Lost coverage with job	(1)	(0)	(-7)	(-8)	(-9)
(d) Don't qualify (ie, Medicaid)	(1)	(0)	(-7)	(-8)	(-9)
(e) No longer on TANF	(1)	(0)	(-7)	(-8)	(-9)
(f) Other	(1)	(0)	(-7)	(-8)	(-9)
<i>(SPECIFY):</i> _____					

[SKIP TO C3]

C2b. Why does [child's name] no longer have health insurance? [*PROBE*: Any other reason?]

	<u>Mention</u>	<u>Not mentioned</u>	<u>INAP</u>	<u>DK</u>	<u>NR</u>
(a) Can't afford it	(1)	(0)	(-7)	(-8)	(-9)
(b) Job doesn't provide	(1)	(0)	(-7)	(-8)	(-9)
(c) Loss coverage with job	(1)	(0)	(-7)	(-8)	(-9)
(d) Don't qualify (ie, Medicaid)	(1)	(0)	(-7)	(-8)	(-9)
(e) No longer on TANF	(1)	(0)	(-7)	(-8)	(-9)
(f) Other	(1)	(0)	(-7)	(-8)	(-9)
<i>(SPECIFY):</i> _____					

C3. When [child's name] is without health insurance, how do you cover the cost of medical care?

[PROBE: Anything else?]

	<u>Mentioned</u>	<u>Not Mentioned</u>	<u>INAP</u>	<u>DK</u>	<u>NR</u>
(a) Pay for it yourself	(1)	(0)	(-7)	(-8)	(-9)
(b) Get free care	(1)	(0)	(-7)	(-8)	(-9)
(c) Treat the child yourself	(1)	(0)	(-7)	(-8)	(-9)
(d) Wait before seeing/don't go to doctor	(1)	(0)	(-7)	(-8)	(-9)
(e) Other	(1)	(0)	(-7)	(-8)	(-9)
(SPECIFY): _____					

C4. Where do you *usually* go when [child's name] is sick, or when you need advice about his/her health?

[PROBE: Any other places?].

	<u>Mentioned</u>	<u>Not mentioned</u>	<u>DK</u>	<u>NR</u>
(a) Hospital clinic	(1)	(0)	(-8)	(-9)
(b) Private physician's office,	(1)	(0)	(-8)	(-9)
(c) Community health center	(1)	(0)	(-8)	(-9)
(d) Public health clinic	(1)	(0)	(-8)	(-9)
(e) HMO	(1)	(0)	(-8)	(-9)
(f) School nurse/clinic	(1)	(0)	(-8)	(-9)
(g) Pharmacist	(1)	(0)	(-8)	(-9)
(h) Herbalist (Botanica)	(1)	(0)	(-8)	(-9)
(i) Emergency room	(1)	(0)	(-8)	(-9)
(j) Other	(1)	(0)	(-8)	(-9)
(SPECIFY): _____				

Now I'm going to ask similar questions about your current and previous health insurance.

[MOTHER INSURANCE]

D

D1. Do you have health insurance *now* (such as Medicaid, CHIP, or private insurance)?

- (1) Yes
- (0) No [SKIP TO D1c]
- (-8) DK
- (-9) NR

D1a. What type of health insurance is it?

- (1) Medicaid
- (2) CHIP (including Family Health Plus)
- (3) Private (through work)
- (4) Private (purchased by individual)
- (5) Other (SPECIFY): _____
- (-7) INAP
- (-8) DK
- (-9) NR

Same specifications as questions in section C.

D1b. Was there any time in the past year that you did *not* have health insurance?

- (1) Yes [SKIP TO D2a]
- (0) No [SKIP TO D4]
- (-7) INAP
- (-8) DK
- (-9) NR

D1c. Did you have health insurance at any time in the past year?

- (1) Yes [SKIP TO D2b]
- (0) No [SKIP TO D3]
- (-7) INAP
- (-8) DK
- (-9) NR

D2a. Why did *you* not have health insurance during that time? [*PROBE*: Any other reason?]

	<u>Mention</u>	<u>Not mentioned</u>	<u>INAP</u>	<u>DK</u>	<u>NR</u>
(a) Can't afford	(1)	(0)	(-7)	(-8)	(-9)
(b) Job doesn't provide	(1)	(0)	(-7)	(-8)	(-9)
(c) Loss coverage with job	(1)	(0)	(-7)	(-8)	(-9)
(d) Don't qualify (ie, Medicaid)	(1)	(0)	(-7)	(-8)	(-9)
(e) No longer on TANF	(1)	(0)	(-7)	(-8)	(-9)
(f) Other	(1)	(0)	(-7)	(-8)	(-9)

(*SPECIFY*): _____

[SKIP TO D3]

D2b. Why do *you* no longer have health insurance? [*PROBE*: Any other reason?]

	<u>Mention</u>	<u>Not mentioned</u>	<u>INAP</u>	<u>DK</u>	<u>NR</u>
(a) Can't afford it	(1)	(0)	(-7)	(-8)	(-9)
(b) Job doesn't provide	(1)	(0)	(-7)	(-8)	(-9)
(c) Loss coverage with job	(1)	(0)	(-7)	(-8)	(-9)
(d) Don't qualify (ie, Medicaid)	(1)	(0)	(-7)	(-8)	(-9)
(e) No longer on TANF	(1)	(0)	(-7)	(-8)	(-9)
(f) Other	(1)	(0)	(-7)	(-8)	(-9)

(*SPECIFY*): _____

D3. So when you are without health insurance, how do you cover the cost of medical care?

[*PROBE*: Anything else?]

	<u>Mentioned</u>	<u>Not Mentioned</u>	<u>INAP</u>	<u>DK</u>	<u>NR</u>
(f) Pay for it yourself	(1)	(0)	(-7)	(-8)	(-9)
(g) Get free care	(1)	(0)	(-7)	(-8)	(-9)
(h) Treat the child yourself	(1)	(0)	(-7)	(-8)	(-9)
(i) Wait before seeing a doctor	(1)	(0)	(-7)	(-8)	(-9)
(j) Other	(1)	(0)	(-7)	(-8)	(-9)

(*SPECIFY*): _____

D4. Where do *you* usually go when you are sick, or need advice about your health? [*PROBE*: Anywhere else?]

	<u>Mentioned</u>	<u>Not mentioned</u>	<u>DK</u>	<u>NR</u>
(a) Hospital clinic	(1)	(0)	(-8)	(-9)
(b) Private physician's office	(1)	(0)	(-8)	(-9)
(c) Community health center	(1)	(0)	(-8)	(-9)
(d) Public health clinic	(1)	(0)	(-8)	(-9)
(e) HMO	(1)	(0)	(-8)	(-9)
(f) School nurse/clinic	(1)	(0)	(-8)	(-9)
(g) Pharmacist	(1)	(0)	(-8)	(-9)
(h) Herbalist (Botanica)	(1)	(0)	(-8)	(-9)
(i) Emergency room	(1)	(0)	(-8)	(-9)
(j) Other	(1)	(0)	(-8)	(-9)

(*SPECIFY*): _____

Some families receive different types of assistance. The first group of questions I am going to ask are about TANF (that is, welfare or cash assistance, what used to be called AFDC).

[TANF/OTHER BENEFITS]
E

E1. Does your family currently receive TANF (“welfare”)?

- (1) Yes [GO TO E1a]
- (0) No (includes recently applied for benefits) [SKIP TO E1b]
- (-8) DK
- (-9) NR

E1a. And who is covered by TANF? Is it . . .

Some Rs may only receive cash benefits for their children—not for themselves. Also, R may receive it, but not the child, because the child may receive SSI due to his/her medical disability.

- (1) your children only, [SKIP TO E1c]
- (2) your children and yourself, or [SKIP TO E1d]
[Interviewer: with or without partner is included here]
- (3) only you? [SKIP TO E1d]
- (-7) INAP
- (-8) DK
- (-9) NR

E1b. Do you not receive TANF because. . .

- (1) you don’t need it or never applied, [SKIP TO E2],
- (2) you applied, but were denied benefits, [SKIP TO E2]
- (3) you used to receive it, but don’t now, or [SKIP TO E1e]
- (4) you recently applied and are waiting
for decision? (never received prior to now) [SKIP TO E2]
- (-7) INAP
- (-8) DK
- (-9) NR

E1c. Do you not receive TANF benefits because. . .

- (1) you don’t need it or never applied, [SKIP TO E2]
- (2) you applied, but were denied benefits, [SKIP TO E2]
- (3) you used to receive it, but don’t now, or [SKIP TO E1e]
- (4) you recently applied and are waiting for
(5) a decision? [SKIP TO E2]
- (-7) INAP
- (-8) DK
- (-9) NR

E1d In the past 4 years (that is, since 1997), was there a time when you stopped receiving TANF, or your benefits were cut or altered in any way?

- (1) Yes [GO TO E1e]
- (0) No [SKIP TO E2]
- (-7) INAP
- (-8) DK
- (-9) NR

R need not have received TANF continuously since 4 years ago, just need to know if previously had TANF, then didn’t have it, but now does.

calendar

E1e.

Did you ...

If R says she reached her time limit, mark 2.

- (1) voluntarily stop receiving TANF, or [GO TO E1f] **“LEFT”**
- (2) were your benefits cut by the TANF agency? [SKIP TO E1g] **“LOST”**
- (-7) INAP
- (-8) DK
- (-9) NR

E1f. Why did you voluntarily stop receiving TANF? [PROBE: Any other reason?]

	<u>Mentioned</u>	<u>Not mentioned</u>	<u>DK</u>	<u>NR</u>
a. Got a job (including a new job, raise, etc.)	(1)	(0)	(-8)	(-9)
b. Started receiving SSI instead	(1)	(0)	(-8)	(-9)
c. Too many requirements to comply with	(1)	(0)	(-8)	(-9)
d. Was embarrassed (stigma)	(1)	(0)	(-8)	(-9)
e. Increase in income (from source other than job)	(1)	(0)	(-8)	(-9)
f. Other	(1)	(0)	(-8)	(-9)

(SPECIFY): _____

[SKIP TO E1h]

E1g. Why were your benefits cut?

	<u>Mentioned</u>	<u>Not mentioned</u>	<u>DK</u>	<u>NR</u>
a. Got a job (including a new job, raise, etc.)	(1)	(0)	(-8)	(-9)
b. Increase in income (from source other than job)	(1)	(0)	(-8)	(-9)
c. Got married	(1)	(0)	(-8)	(-9)
d. Didn't comply with TANF rules	(1)	(0)	(-8)	(-9)

(SPECIFY): _____

e. Reached time limit	(1)	(0)	(-8)	(-9)
f. Other	(1)	(0)	(-8)	(-9)

(SPECIFY): _____

E1h. How long has it been since you last received TANF?

Circle weeks or months depending on R's answer

_____ weeks / months

- (-7) INAP
- (-8) DK
- (-9) NR

calendar

[INTERVIEWER: circle either weeks or months]

E2. Now with regard to other benefits, do you currently receive...

We are referring to subsidized housing

	<u>Yes</u>	<u>No</u>	<u>DK</u>	<u>NR</u>
a. child care benefits?	(1)	(0)	(-8)	(-9)
b. <u>WIC?</u>	(1)	(0)	(-8)	(-9)
c. <u>housing benefits?</u>	(1)	(0)	(-8)	(-9)

WIC is the Supplemental Program for Women, Infants and Children. This is a program that provides nutritional supplements and baby supplies such as diapers for low-income families.

E3. With regard to Food Stamps, do you receive them . . .

- (1) solely for yourself,
- (2) solely for your child(ren),
- (3) for all of you, or
- (0) not at all?

- (-8) DK
- (-9) NR

E4. With regard to SSI do you receive this. . .
 (SSI=Supplemental Security Income assistance for individuals with permanent disabilities.)

- (1) solely for yourself,
- (2) solely for your child,
- (3) for both of you, or
- (0) not at all?
- (-8) DK
- (-9) NR

E5. Some families have had difficulties in some of the following areas.
 In the past 6 months, have *you* had a problem with. . .

	<u>Yes</u>		<u>No</u>	<u>DK</u>	<u>NR</u>
a. housing (eg, paying rent, having to move in with friends, family)?	(1)	Explain: _____	(0)	(-8)	(-9)
b. not enough food at home?	(1)	Explain: _____	(0)	(-8)	(-9)
c. phone service being cut off?	(1)	Explain: _____	(0)	(-8)	(-9)
d. utility service being cut off (electric, gas, heat)?	(1)	Explain: _____	(0)	(-8)	(-9)
f. any other similar problems?	(1)	Explain: _____	(0)	(-8)	(-9)

E6. Do you own a car?

- (1) Yes
- (0) No [SKIP to F1]
- (-8) DK
- (-9) NR

E6a. In the past 6 months, have you had a problem with your car breaking down or needing repair?

- (1) Yes *Explain:* _____
- (0) No
- (-7) INAP
- (-8) DK
- (-9) NR

These next few questions are about work.

[EMPLOYMENT]

F

F1. Are you currently working outside your home?

- (1) Yes
- (0) No [*PROBE:* Not at all? Not even part-time?] [SKIP TO F1c]
- (-8) DK
- (-9) NR

F1a. Is this a...

Workfare means R isn't paid by the organization where she works, rather, she is working in order to receive her TANF check.

- (1) a part- or full-time job *not* associated with TANF, or
- (2) a workfare position (through the TANF office)?
- (3) Other _____
- (-7) INAP

(-8) DK
 (-9) NR

F1b. How many hours a week do you usually work at this and any other job altogether?
 [INTERVIEWER: insert number; if less than 10hrs/week, enter a zero and then the number.]

___ ___ hours [SKIP TO F3] (-7) INAP
 (-8) DK
 (-9) NR

F1c. Have you worked outside the home *anytime* in the *past 4 years* (that is, since around the time welfare reform began in 1997?)

(1) Yes [SKIP TO F3]
 (0) No [GO TO F1d]
 (-7) INAP
 (-8) DK
 (-9) NR

F1d. During this time, did you try to *find* or did you *want* to work?

(1) Yes
 (0) No [SKIP TO next section **Box G**]
 (-7) INAP
 (-8) DK
 (-9) NR

F2. Have any of the following made it difficult for you to find work/a job?

	<u>Yes</u>	<u>No</u>	<u>INAP</u>	<u>DK</u>	<u>NR</u>
a. Your child's health?	(1)	(0)	(-7)	(-8)	(-9)
b. Your health?	(1)	(0)	(-7)	(-8)	(-9)
c. The health of another family member?	(1)	(0)	(-7)	(-8)	(-9)
d. Lack of child care?	(1)	(0)	(-7)	(-8)	(-9)
e. Any other reason?	(1)	(0)	(-7)	(-8)	(-9)

Read and record a response for each item.

(SPECIFY): _____

[SKIP TO next section **Box G**]

F3. In the past 4 years, has...

	<u>(A)</u> <u>...made it hard for you to find a job?</u>					<u>(B)</u> <u>...caused you to miss work?</u>					<u>(C)</u> <u>...caused you to lose a job?</u>				
	<u>Yes</u>	<u>No</u>	<u>INAP</u>	<u>DK</u>	<u>NR</u>	<u>Yes</u>	<u>No</u>	<u>INAP</u>	<u>DK</u>	<u>NR</u>	<u>Yes</u>	<u>No</u>	<u>INAP</u>	<u>DK</u>	<u>NR</u>
a. your child's health ...	(1)	(0)	(-7)	(-8)	(-9)➤	(1)	(0)	(-7)	(-8)	(-9)➤	(1)	(0)	(-7)	(-8)	(-9)
b. your own health ...	(1)	(0)												(-8)	(-9)
c. the health of another family member ...	(1)	(0)												(-8)	(-9)
d. lack of childcare...	(1)	(0)												(-8)	(-9)
e. any other thing...	(1)	(0)												(-8)	(-9)

(SPECIFY): Ask the question in column A, B, and C for each of the items listed. Repeat the question stem for each new item for example, "In the past 3 years, has your own health..."
 For question e, *do not forget* to fill in the line specifying the "other thing" that has made it hard to find a job, etc.

These next questions are about child care.

[CHILD CARE]

G

BOX G: - If R “currently working” (F1, pg. 13) : GO TO G1
 - If R “not currently working” ask : Are you in school or in a job training program? (1) Yes [GO TO G1]
 (2) No [SKIP TO G3]

G1. Who usually takes care of [child’s name] while you are working/in school/at job training? [*PROBE:* Anyone else?]

	<u>Mentioned</u>	<u>Not Mentioned</u>	<u>INAP</u>	<u>DK</u>	<u>NR</u>
a. Child in school	(1)	(0)	(-7)	(-8)	(-9)
b. Other parent	(1)	(0)	(-7)	(-8)	(-9)
c. Grandparent	(1)	(0)	(-7)	(-8)	(-9)
d. Child cares for self	(1)	(0)	(-7)	(-8)	(-9)
e. Older sibling <i>Age: _____</i>	(1)	(0)	(-7)	(-8)	(-9)
f. Other relative	(1)	(0)	(-7)	(-8)	(-9)
g. Babysitter	(1)	(0)	(-7)	(-8)	(-9)
h. Informal, home-based day care	(1)	(0)	(-7)	(-8)	(-9)
i. Day Care center	(1)	(0)	(-7)	(-8)	(-9)
j. Afterschool program	(1)	(0)	(-7)	(-8)	(-9)
k. Night/evening care	(1)	(0)	(-7)	(-8)	(-9)
l. Other	(1)	(0)	(-7)	(-8)	(-9)
<i>(SPECIFY): _____</i>					

G2. What happens with your child care arrangement when your child is sick? [*PROBE:* That is, is your child still cared for in the same way, or is that not possible? How so?]

<hr style="border: none; border-top: 1px solid black;"/> <hr style="border: none; border-top: 1px solid black;"/> <hr style="border: none; border-top: 1px solid black;"/>	We want to know what arrangements R has for times when the child is sick.	<hr style="border: none; border-top: 1px solid black;"/> <hr style="border: none; border-top: 1px solid black;"/> <hr style="border: none; border-top: 1px solid black;"/>
--	---	--

(-7) INAP (-8) DK (-9) NR

G3. Has your child’s health problem made it . . . to find child care when you need it?

- (1) harder,
- (2) easier, or
- (3) made no difference
- (-8) DK
- (-9) NR

These next set of questions are about how you feel and how things have been with you during the last 6 months. For each question, please give the one answer that comes closest to the way you have been feeling from responses on the card. Remember that your answers are strictly confidential and that you don't have to answer a question if don't want to.

[MH]
H

How much of the time during the last 6 months, have you....

H1. ...been a very nervous person?

- (5) all of the time,
- (4) most of the time,
- (3) a good bit of the time,
- (2) some of the time,
- (1) a little of the time, or
- (0) none of the time?
- (-8) DK
- (-9) NR

-Use the response card so that R may have the answer options in front of her for each question.

-Ask her to provide you with the number corresponding to her answer.

-Allow R to read the questions to herself if she appears more comfortable with that.

Response
Card

H2. ...felt calm and peaceful?

- (5) all of the time,
- (4) most of the time,
- (3) a good bit of the time,
- (2) some of the time,
- (1) a little of the time, or
- (0) none of the time?
- (-8) DK
- (-9) NR

H3. ...felt downhearted and blue?

- (5) all of the time,
- (4) most of the time,
- (3) a good bit of the time,
- (2) some of the time,
- (1) a little of the time, or
- (0) none of the time?
- (-8) DK
- (-9) NR

H4. ...been a happy person?

- (5) all of the time,
- (4) most of the time,
- (3) a good bit of the time,
- (2) some of the time,
- (1) a little of the time, or
- (0) none of the time?
- (-8) DK
- (-9) NR

QH5. ...felt so down in the dumps that nothing could cheer you up?

- (5) all of the time,
- (4) most of the time,
- (3) a good bit of the time,
- (2) some of the time,
- (1) a little of the time, or
- (0) none of the time?
- (-8) DK

For the next few questions keep in mind that “drug use” can refer to the use of street drugs such as marijuana (or pot), cocaine, amphetamines (speed), and heroin, as well as prescription drugs taken in excess of recommended amounts. “Drinking” refers to any beverage that contains alcohol such as beer, wine, wine coolers, and liquor. Again, your responses to these questions are confidential.

[SA]
I

11. Have you *ever* felt you should cut down on your drinking or drug use?

(1) Yes

(0) No

[INTERVIEW: For Rs who report never drank or used any drugs, also code “0”.]

(-8) DK

(-9) NR

12. Have people *ever* annoyed you by criticizing your drinking or use of drugs?

(1) Yes

(0) No

(-8) DK

(-9) NR

13. Have you *ever* felt bad or guilty about drinking or using drugs?

(1) Yes

(0) No

(-8) DK

(-9) NR

14. Have you *ever* taken a drink or a drug first thing in the morning (“eye-opener”) to steady your nerves or get rid of a hangover?

(1) Yes

(0) No

(-8) DK

(-9) NR

15: In the past *year*, has drinking or taking drugs interfered with doing something important, like working, going to school or taking care of your family?

(1) Yes

(0) No

(-8) DK

(-9) NR

Some women may experience some form of abuse in their relationships, so these final questions are about any violence or abuse you may have experienced.

[DV]
J

J1. Do you feel safe in your current relationship?

Note that if R is not in a relationship, mark 2.
By "relationship, we mean any sort of romantic relationship. R does not have to be living with the person.

- (1) Yes
- (0) No
- (2) Not currently in a relationship
- (-8) DK
- (-9) NR

J2. Is there a partner from a previous relationship who is making you feel unsafe now?

- (1) Yes
- (0) No
- (-8) DK
- (-9) NR

J3. In the past six months, have you been hit, kicked, punched or otherwise hurt by someone?

- (1) Yes
- (0) No [SKIP TO K1]
- (-8) DK
- (-9) NR

J3a. If so, by whom?

- (1) Spouse
- (2) Boyfriend/Girlfriend
- (3) Parent
- (4) Other family member (*SPECIFY*): _____
- (5) Stranger
- (6) Other (*SPECIFY*): _____
- (-7) INAP
- (-8) DK
- (-9) NR

J3b. Did you need to see a doctor or go to the hospital?

- (1) Yes
- (0) No
- (-7) INAP
- (-8) DK
- (-9) NR

This last set of questions covers some general information about yourself.

[DEMOGRAPHIC]

K

K1. What is the highest grade or year in school that you have completed?

____ years

46

Example: If R completed high school, code as "12". If attended college, add number of years to that,(eg, 2 years of college would be coded as "14."

K2. What is the highest degree you have ever received?

- (1) None/did not complete high school
- (2) High school diploma/GED
- (3) Vocational/technical/business degree, certificate or license
- (4) Associates
- (5) Bachelors
- (6) Masters/other professional
- (-8) DK
- (-9) NR

K3. With regard to your marital status, are you...

- (1) single (or separated/widowed),
- (2) legally married (*and* living together), or
- (3) living with your partner, but not married?
- (-8) DK
- (-9) NR

If R is divorced, separated or widowed AND is not living with a current partner mark 1.

K4. How would you identify yourself racially or ethnically?

[INTERVIEWER: **DO NOT READ**, CODE 1ST RESPONSE OR PROBE ONLY FOR ONE]

- (1) Dominican
- (2) White/ Anglo
- (3) Black/African American
- (4) Other (*SPECIFY*): _____
- (-8) DK
- (-9) NR

K5. Were you born in this country?

- (1) Yes
- (0) No *Which country?*: _____
- (-8) DK
- (-9) NR

K6. How old are you?

___ ___ years

K7. What language do you speak most comfortably?

- (1) English
- (2) Spanish
- (3) Both
- (4) Other (*SPECIFY*): _____
- (-8) DK
- (-9) NR

K8. How many people are currently living with you or staying in your home (including other relatives or friends)?

___ ___

K9. Finally, please use this card and tell me which number is closest to your total household income. By total income I mean all money coming into your household every month from any jobs that you or another adult have, including public assistance, and from friends or relatives, child support, or any other source.

- (1) Under \$250 per month (under \$3,000 per year)
- (2) \$251-\$500 per month (\$3,012 - \$6,000 per year)
- (3) \$501-\$999 per month (\$6,012 - \$11,988 per year)
- (4) \$1000-\$1499 per month (\$12,000 - \$17,988 per year)
- (5) \$1500-\$1999 per month (\$18,000 - \$23,988 per year)
- (6) \$2000-\$2499 per month (\$24,000 - \$29,988 per year)
- (7) \$2500-\$2999 per month (\$30,000 - 35,988 per year)
- (8) \$3000 or above per month (\$36,000 and above per year)
- (-8) DK
- (-9) NR

Ask R to provide you with the number that corresponds to her monthly household income.

Response card



**LOCATING PAGE: BASELINE SURVEY
(NYC)**

INTERVIEWER: DETACH THIS PAGE FROM QUESTIONNAIRE

This brings us to the end of the survey. I want to thank you very much for your time. You've been very patient and helpful. We hope that your responses to these questions might help to improve health and social services for women and their children. As part of this project, we plan to contact you again (by telephone) in approximately 6 months. Would you please give me your address and phone number so I can contact you.

Child's name: _____

Mother's name: _____

Address: _____

City: _____ State: _____ Zip code: _____

Home phone number: _____ - _____ - _____

Work phone number: _____ - _____ - _____

Any additional numbers, such as pager or cell:

Pager: _____ - _____ - _____ Cell phone: _____ - _____ - _____

In case your number changes or you move, I want to ask you for two other ways I can contact you. I need the names of two other people (like your mother, sister, or friends) who would know how to contact you.

First contact name: _____

Relationship to R: _____

Address: _____

City: _____ State: _____ Zip code: _____

Phone number: _____ - _____ - _____

Second contact name: _____

Relationship to R: _____

Address: _____

City: _____ State: _____ Zip code: _____

Phone number: _____ - _____ - _____

Be sure to have respondent sign below to verify that the survey was completed and she received the gift card.

After completing the survey, I received a telephone calling card ("gift card"): _____
Signature _____ Date _____

FORMS