

Cognitive Testing of 2014 SIPP Disabilities Module Cognitive Interview Protocol Guide

PARTICIPANT ID #: _____

DATE: ___ / ___ / 2013

COGNITIVE INTERVIEWER NAME:

START TIME: ____: ____ AM / PM

SECTION I. INTERVIEW CONSENT

(COGNITIVE INTERVIEWER: READ)

PLACE THE CONSENT FORM IN FRONT OF PARTICIPANT

- A. Hello, I'm [NAME OF COGNITIVE INTERVIEWER]. I work for the Census Bureau. Thanks for agreeing to help me today.**

Before we start, I would like you to read over the document in front of you. This document explains a little bit about this interview and provides information about your rights as a participant. It also asks for your permission to have this session audio recorded. Please ask me any questions you have about this document. Once you have finished reading the document, please sign it.

- PARTICIPANT READS AND SIGNS FORM

- B. IF PARTICIPANT PROVIDES CONSENT TO HAVE THE SESSION AUDIO-TAPED: I will now turn on the tape recorder.**

TEST TAPE RECORDER AND TURN IT ON AGAIN AFTER TEST

SECTION II. COGNITIVE INTERVIEW

A. Introduction

(COGNITIVE INTERVIEWER: READ/PARAPHRASE)

“Let me begin by telling you a little more about what we’ll be doing today. The United States Census Bureau counts the population in the U.S and also conducts various kinds of surveys.

Today, with your help, we will be testing some new questions that were developed for a national survey called the Survey of Income and Program Participation. I will first ask you some survey questions and you’ll answer the questions just like you would if you were doing it with an interviewer in a regular survey. We are interested in how you understand these questions and how these questions work for you. I am interested in your answers, but I am also interested in the process you go through in your mind when you answer the questions. So I’d like you to think aloud as you answer the questions, just tell me everything you are thinking about as you go about answering each question. From time to time, I’ll ask you some questions about your answers, or about the questions themselves.

Our goal here is to get a better idea how well the new questions work with people such as yourself before we actually use them in the survey. So the purpose of our session today is to collect your thoughts and opinions on these new questions and materials. I just want to remind you that I’m only asking for your thoughts and opinions on these materials. There is no right or wrong answer. We are simply trying to make sure the question wording is clear and easy for most people to understand. Your feedback will be very useful for helping make sure these questions will make sense to other people.

Your participation in this interview and the review of the materials is very important because it will help the Census Bureau with improving these questions.

Do you have any questions before we begin?”

A. THINK-ALoud PRACTICE

Let’s begin with a practice question. Remember to try to think aloud as you answer.

Practice Question 1. How many windows are there in the house or apartment where you live? WINDOWS _____

[IF NEEDED:] Try to visualize the place where you live, and think about how many windows there are in that place. As you count up the windows, tell me what you are seeing and thinking about.

PROBES:

- How did you come up with that answer?
- Tell me more about that. Why did you say [ANSWER]?
- I noticed that you hesitated. Tell me what you were thinking.

NOTE TO COGNITIVE INTERVIEWER: START INTERVIEW. NOTE ANY PROBLEMS/COMMENTS/QUESTIONS/PUZZLED LOOKS/EXASPERATED SIGHS RESPONDENT HAS DURING THE INTERVIEW. WHEN NECESSARY, PROBE ON THESE AFTER THE RESPONDENT ANSWERS THE QUESTION.

- a. What is your name? _____
- b. What is your age? ♦(FR instruction: Report age in years.)
- 1 17 years old or younger -- End SIPP Module and go to Debriefing Questions on p. 15
 - 2 18 to 72 years old
 - 3 73 years old or older - Skip to question 7

WORK DISABILITY

1. I have some questions about health conditions that affect the kind or amount of work a person can do at a job or business.

Do you have a long-lasting physical or mental condition that has made it difficult to remain employed or to find a job?

- 1 Yes
 - 2 No
 - 3 Dk
 - 4 Refuse
- } -- Skip to question 3

PROBE:

- What kind of conditions were you thinking about when you answered this question?
 - How much time do you think is meant by “long-lasting” in this question?
2. To what extent does your condition make it difficult to remain employed or find a job? ♦(FR instruction: Read answer categories.)

- 1 Extremely difficult (cannot find or keep a job)
 - 2 Very difficult
 - 3 Difficult
 - 4 Somewhat difficult
- ♦(FR instructions: DO NOT READ.)
- 5 Dk
 - 6 Ref

PROBE:

- If not stated already: Can you tell me more about your answer?
- What does this question mean in your own words?
- Did you have any difficulty coming up with your answer to this question?

3. Do you currently have a job or business, or do any kind of work for pay?

- 1 Yes -- Skip to question 7
- 2 No
- 3 Dk
- 4 Refuse

4. Does your health or condition prevent you from working at a job or business?

- 1 Yes
 - 2 No
 - 3 Dk
 - 4 Refuse
- } -- Skip to question 7

PROBE:

- If response not already described in detail: Can you tell me more about that?

5. At what age did you become unable to work at a job or business?

		Age
--	--	-----

- 73 Person has NEVER been able to work at a job -- Skip to question 7
- 74 Dk
- 75 Refuse

PROBE:

- If not already stated: How did you come up with your answer to this question?

6. How likely are you to work in the future?

◆ (FR instruction: Read answer categories.)

- 1 Extremely likely (will definitely work in the future)
- 2 Somewhat likely
- 3 Unlikely
- 4 Very unlikely
- 5 Extremely unlikely (will definitely not work in the future)

◆ (FR instructions: DO NOT READ.)

- 6 Dk
- 7 Refuse

PROBE:

- **If not stated already: Can you tell me more about your answer?**
- **Did you have any difficulty coming up with the answer to this question?**

ADULT DISABILITY

7. The next set of questions help us learn about people who have physical, mental, or emotional conditions that cause serious difficulty with their daily activities.

As of today, would you say your health in general is excellent, very good, good, fair, or poor?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor
- 6 Dk
- 7 Refuse

PROBE:

- **If not stated already: Can you tell me more about your answer?**
- **Did you have any difficulty coming up with the answer to this question?**

8. Do you use:

◆ (FR instruction: Mark by observation, if apparent.)

- a. **a cane, crutches, or a walker?** 1 Yes 2 No 3 Dk 4
Refuse

- b. **a wheelchair, electric chair, or
similar aid for getting around?** 1 Yes 2 No 3 Dk 4
Refuse

- c. **a hearing aid?** 1 Yes 2 No 3 Dk 4
Refuse

9. As of today, are you blind or do you have serious difficulty seeing, even when wearing glasses or contacts?

- 1 Yes
- 2 No
- 3 Dk
- 4 Refuse

PROBE:

- **If not stated already: Can you tell me more about your answer?**
- **What would be an example of having “serious difficulty” seeing?**

□

10. As of today, are you deaf or do you have serious difficulty hearing?

- 1 Yes
- 2 No
- 3 Dk
- 4 Refuse

PROBE:

- **If not stated already: Can you tell me more about your answer?**
- **What would be an example of having “serious difficulty” hearing?**

11. Do you have difficulty having your speech understood in the language spoken in the home?

◆ (FR instruction: Do not enter "1" for "yes" if the person had trouble simply because they speak a language other than English.)

- 1 Yes
- 2 No
- 3 Dk
- 4 Refuse

PROBE:

- **If not already stated: How did you come up with your answer to this question?**

12. Do you have any difficulty lifting and carrying something as heavy as 10 pounds - such as a bag of groceries?

- 1 Yes -- *Skip to question 14*
- 2 No
- 3 Dk
- 4 Refuse

PROBE:

- **If response not already described in detail: Can you tell me more about that?**

13. Would you have any difficulty lifting and carrying a 25-pound bag of pet food?

- 1 Yes
- 2 No
- 3 Dk
- 4 Refuse

PROBE:

- **If not already stated: How did you come up with your answer to this question?**

14. Do you have any difficulty pushing or pulling large objects such as a living room chair?

- 1 Yes
- 2 No
- 3 Dk
- 4 Refuse

15. Do you have any difficulty:

a. standing or being on your feet for one hour?

Refuse

- 1 Yes 2 No 3 Dk 4

b. sitting for one hour?

Refuse

- 1 Yes 2 No 3 Dk 4

c. stooping, crouching, or kneeling?

Refuse

- 1 Yes 2 No 3 Dk 4

d. reaching over your head?

Refuse

1 Yes 2 No 3 Dk 4

PROBE:

- **If yes to c: Can you tell me more about that?**
- **If yes to d: Can you tell me more about that?**

16. Do you have difficulty using your hands and fingers to do things such as picking up a glass or grasping a pencil?

- 1 Yes
2 No
3 Dk
4 Refuse

17. Do you have any difficulty walking up a flight of 10 stairs?

- 1 Yes
2 No
3 Dk
4 Refuse

18. Do you have any difficulty walking a quarter of a mile - about 3 city blocks?

- 1 Yes
2 No
3 Dk
4 Refuse

19. Do you have any difficulty using an ordinary telephone?

- 1 Yes
2 No
3 Dk
4 Refuse

PROBE:

- **What does an “ordinary telephone” mean to you in this question?**

20. Because of a physical or mental health condition, do you have difficulty doing any of the following by yourself?

◆ (FR instruction: If an aid is used, ask whether the person has difficulty when using the aid.)

a. Getting around INSIDE the home? 1 Yes 2 No 3 Dk 4
Refuse

b. Going OUTSIDE the home to run errands, like to shop or visit a doctor's office? 1 Yes 2 No 3 Dk 4
Refuse

c. Getting in or out of bed or a chair? 1 Yes 2 No 3 Dk 4
Refuse

d. Taking a bath or shower? 1 Yes 2 No 3 Dk 4
Refuse

e. Dressing? 1 Yes 2 No 3 Dk 4
Refuse

f. Walking? 1 Yes 2 No 3 Dk 4
Refuse

g. Eating? 1 Yes 2 No 3 Dk 4
Refuse

h. Using or getting to the toilet? 1 Yes 2 No 3 Dk 4
Refuse

i. Keeping track of money or bills? 1 Yes 2 No 3 Dk 4
Refuse

j. Preparing meals? 1 Yes 2 No 3 Dk 4
Refuse

k. Doing light housework such as washing dishes or sweeping a floor? 1 Yes 2 No 3 Dk 4
Refuse

l. Taking the right amount of

prescribed medicine at the
right time?
Refuse

1 Yes 2 No 3 Dk 4

m. Using a computer?
Refuse

1 Yes 2 No 3 Dk 4

n. Using the Internet?
Refuse

1 Yes 2 No 3 Dk 4

PROBE:

- **If not stated already: Can you tell me more about your answer (to M and N)?**
- **Did you have any difficulty coming up with an answer to these questions (M and N)?**
- **For “M”: When thinking of your answer, what kinds of uses were you thinking about for using a computer?**
- **For “N”: When thinking about your answer, what kinds of uses were you thinking about for using the internet?**

Check Item 1: Refer to questions 8-20: Is there at least one “Yes” answer? Yes__ No __.
Question 7 = ___

Refer to Check
Item 1:

- If there is a “Yes” answer to at least one question in questions 8 – 20 -- Continue with question 21.
- If there are no “Yes” answers in questions 8 – 20, AND question 7 equals (#4 or #5) -- Skip to question 22.
- If there are no “Yes” answers in questions 8 – 20, AND question 7 does NOT equal (#4 or #5) -- Skip to question 26

21. ♦ (FR instruction: Refer to CONDITIONS ANSWER LIST. Do NOT show it to the respondent.)

I have recorded that you have difficulty with certain activities. Which condition or conditions cause these difficulties? (Any others?)

♦ (FR instruction: Enter up to THREE conditions that apply.)

♦ (FR instruction: Enter “0” for none in “First condition”.)

First condition

Second condition

Third condition

40 Dk

41 Refuse

PROBE:

- **If R hesitates: How did you come up with your answer?**

Refer to Check Item 1 on page 7:

- If only 1 condition is entered in question 21 -- Skip to question 24.
- If 2 or 3 conditions are entered in question 21 -- Skip to question 23.
- If "0", Dk, or Refuse is entered -- Skip to question 26.

22. ♦ (FR instruction: Refer to CONDITIONS ANSWER LIST. Do NOT show it to the respondent.)

I have recorded that your health is fair or poor. Which condition or conditions cause your health problems? (Any others?)

♦ (FR instruction: Enter up to THREE conditions that apply.)

♦ (FR instruction: Enter "0" for none in "First condition".)

First condition

Second condition

Third condition

40 Dk

41 Refuse

Refer to Check Item 1 on page 7:

- If only 1 condition is entered in question 26 -- Skip to question 24.
- If 2 or 3 conditions are entered in question 26 -- Continue with question 23.
- If "0", Dk, or Refuse is entered -- Skip to question 26.

23. Which of the conditions that you mentioned do you consider to be the main reason for your difficulties?

◆ (FR instruction: Refer to CONDITIONS ANSWER LIST, if necessary.)

		Main condition
--	--	----------------

40 Dk

41 Refuse

PROBE:

- **If not stated already: Can you tell me more about your answer?**
- **Did you have any difficulty coming up with an answer to these questions?**

24. Was this a gradual onset condition that became worse over time, or was it a sudden onset condition that began to affect you immediately?

1 Gradual onset

2 Sudden onset

3 Dk

4 Refuse

PROBE:

- **If not stated already: Can you tell me more about your answer?**
- **Did you have any difficulty coming up with your answer to this question?**
- **What is this question asking in your own words?**

25. At what age did your (main) condition first begin to bother you?

		Age
--	--	-----

97 Condition has been present since birth

98 Dk

99 Refuse

PROBE:

If R hesitates: How did you come up with your answer?

26. This next question is about computer usage.

Approximately how often do you use a computer or laptop in any location, (that is, your home, work, and/or school)?

◆ (FR instruction: Read answer categories, if necessary.)

- 1 Daily
- 2 At least once a week
- 3 At least once a month
- 4 Less than once a month
- 5 Never

◆ (FR instructions: DO NOT READ.)

- 6 Dk
- 7 Refuse

PROBE:

- **If not stated already: Can you tell me more about your answer?**
- **Did you have any difficulty coming up with your answer to this question?**

CHILD DISABILITY

27. The next few questions ask about any physical or mental conditions that a child may have.

Do you have at least one child who is 5 to 17 years old who lives in your household?

- 1 Yes
 - 2 No
 - 3 Dk
 - 4 Refuse
- } -- End SIPP Module and go to Debriefing Questions on p. 15

28. Does your child have a serious physical or mental condition, a congenital condition, or a developmental delay that limits ordinary activities appropriate for the child's age?

If necessary: Developmental delay is slowness in development that causes the child to be unable to perform activities that other children of the same age perform.

A congenital condition is a condition that develops before birth or at the time of birth, and may be caused by hereditary or environmental reasons.

- 1 Yes
- 2 No
- 3 Dk
- 4 Refuse

PROBE:

- **If not stated already: Can you tell me more about your answer?**
- **What does “congenital condition” in this question mean to you?**
- **What are examples of activities you think are appropriate for your child’s age?**
- **Did you have any difficulty coming up with your answer to this question?**

29. Does your child have:

◆ (FR instruction: DO NOT attempt to define these conditions. If a respondent is not familiar with a condition, assume that the child does not have the condition.)

If necessary: A developmental or intellectual disability is a chronic condition that will remain with the child throughout the rest of his or her life.

A developmental condition is a condition that has slowed the development of the child, but may disappear over time.

a. a learning disability such as dyslexia?

Refuse

1 Yes 2 No 3 Dk 4

b. an Intellectual disability (formerly known as Mental retardation?)

Refuse

1 Yes 2 No 3 Dk 4

c. a developmental disability such as autism or Cerebral Palsy?

Refuse

1 Yes 2 No 3 Dk 4

d. Attention Deficit Hyperactivity

- Disorder (ADHD)? 1 Yes 2 No 3 Dk 4
Refuse
- e. a mental illness, affective or personality disorder, or conduct disorder? 1 Yes 2 No 3 Dk 4
Refuse
- f. any other developmental condition for which your child has received therapy or diagnostic services? 1 Yes 2 No 3 Dk 4
Refuse

PROBE:

- If not stated already for “E”: Can you tell me more about your answer?
- For “E”: Did you have any difficulty coming up with your answer to this question?
- If no to “E”: Can you give me any examples of these conditions (i.e., mental illness, affective or personality disorder, or conduct disorder)?

SECTION III. DEBRIEFING QUESTIONS

AFTER THE INTERVIEW:

Now, I am going to ask you some questions about your answers and about the questions themselves. I am really interested in how these questions work for you, so there are no right or wrong answers.

- Overall, what did you think of this interview? Was it easy or difficult?
- Have you ever answered survey questions about disabilities for you or your children in the past? If yes, what was the survey? What was the experience like for you?

JUST A FEW FINAL QUESTIONS TO WRAP UP –

- Overall, do you think some people might find these questions sensitive?
- Do you have anything else you would like to tell us that you haven’t had a chance to mention yet?

I want to thank you very much for your participation. I will now give you \$40 and I will ask you to sign a receipt form verifying that you received the money.

TURN OFF THE TAPE RECORDER. HAND THE CASH INCENTIVE TO THE PARTICIPANT.

COGNITIVE INTERVIEWER ONLY: ANSWER THESE QUESTIONS AFTER THE INTERVIEW.

HOW DIFFICULT WAS IT FOR YOU TO CONDUCT THE INTERVIEW WITH THIS RESPONDENT?

1 Very difficult 2 Somewhat difficult 3 Somewhat easy 4 Very easy

WHAT FACTOR DO YOU THINK ATTRIBUTE TO THIS RESPONDENT'S COGNITIVE INTERVIEW MOST?

1 Age 2 Education 3 Others (Specify: _____)

END TIME: ____: ____ AM / PM

CONDITIONS ANSWER LIST

0	None, no conditions
1	Allergy or immune problem (including food, drug, or skin)
2	Alzheimer's disease or dementia
3	Anemia or blood disorders (like Leukemia)
4	Arthritis or joint/pain problems (including carpal tunnel syndrome)
5	Attention Deficit Disorder (ADD/ADHD)
6	Autism Spectrum Disorders
7	Back or spine problems (including chronic stiffness and deformity)
8	Blindness or vision problem
9	Broken bones or torn ligaments
10	Cancers, growths, or tumors
11	Cerebral Palsy
12	Deafness or hearing problem
13	Depression or anxiety
14	Diabetes
15	Drug or alcohol use problem
16	Dyslexia or learning disability
17	Epilepsy or seizures
18	Fibromyalgia or lupus
19	Head or spinal cord injury
20	Heart trouble
21	Hernia
22	High blood pressure or other circulation problem
23	Impaired or missing extremities or limbs
24	Infectious diseases (including AIDS)
25	Intellectual disability (formerly known as Mental retardation)
26	Kidney or bladder problems
27	Lung or respiratory problems (including asthma or respiratory allergies)
28	Migraine headaches
29	Multiple Sclerosis (MS)
30	Muscular Dystrophy (MD) or other muscle pain or weakness
31	Obesity or weight problem
32	Other developmental problem
33	Other psychological illness
34	Paralysis
35	Parkinson's Disease or other tremors
36	Problems of the reproductive organs
37	Stomach or intestinal trouble (including ulcers or liver conditions)
38	Thyroid or other endocrine problems
39	Other condition

CONDITIONS ANSWER LIST

- ◆ (FR instruction: If the respondent mentions a condition that is not specified on the answer list, before you enter it as 39 - Other condition, check to see if it is listed below. Each number corresponds to the value on the front of this CONDITIONS ANSWER LIST.)

1 - Allergies include food, environmental, drug, and insect bites. Immune problems include Celiac disease, Psoriasis, excema, and Guillain-Barre Syndrome.

4 - Joint and pain disorders include Rheumatism and Carpal tunnel syndrome.

6 - Autism Spectrum Disorders include Asperger's.

10 - Growths and tumors can be benign and include cysts.

12 - Hearing problems include chronic ear infections, especially in children.

20 - Heart trouble includes heart attacks, arrhythmia, and congestive heart disease.

22 - Circulation problems include stroke, hardening of the arteries, blood clots, and hemorrhage.

24 - Infectious diseases include AIDS, AIDS related condition (ARC), the flu, strep throat, pneumonia.

26 - Bladder problems include urinary tract infections (UTIs).

27 - Lung or respiratory problems include bronchitis, emphysema, hay fever, and tuberculosis.

32 - Developmental problems include Fragile X syndrome, Rett syndrome, Prader-Willi syndrome, Trisomy 18, and other birth defects.

33 - Psychological illnesses include Schizophrenia, Anorexia, Obsessive-compulsive disorder (OCD), Post-Traumatic Stress disorder (PTSD), and Dissociative identity disorder.

35 - Tremors include Essential tremor, Tourette's, and tic disorders.

36 - Reproductive organ problems include ovaries, uterus, and prostate.

37 - Stomach and intestinal problems include digestive diseases like chronic heartburn, Inflammatory bowel disease, gallbladder, and colorectal diseases like Crohn's disease, colitis, diverticulosis, hemorrhoids, and Irritable bowel syndrome. Liver conditions include Hepatitis A, B or C, cirrhosis, and metabolism problems like cholesterol and glycogen.

38 - Endocrine conditions include pituitary disorders, growth hormone disorders, goiters, Grave's disease, gout, and Cushing's disease.