

# OPWDD MONEY FOLLOWS THE PERSON QUALITY OF LIFE SURVEY PROXY GUIDELINES

**Below is information to help guide the decision to conduct a proxy interview, and the procedures to you. Both the guidance and the instructions were developed by Mathematica Policy Research.**

## **MATHEMATICA Money Follows the Person Quality of Life Interviewer Training Manual**

### **Proxy and Assisted Interviews**

A proxy respondent is a person who answers the survey questions on the program participant's behalf, often because the program participant is unable to do so. It is permissible to allow the respondent to be assisted by a friend or family member if they require help to complete the survey or, if necessary, to conduct the interview with a proxy who is very familiar with the program participant's situation and agrees to answer on his or her behalf. Program participants, however, are the best judge of their own experiences and their responses should be solicited whenever possible.

Often times proxy respondents give the impression that the respondent is less healthy than he or she actually is.

While the sample person should respond for him or herself whenever possible, a proxy response is better than no response and program participants should not be badgered to complete the interview.

#### **1. Determining when an assisted interview or proxy may be necessary**

There are three situations in which an assisted interview or proxy may be necessary:

1. The program participant wants to complete the interview, but you believe that he or she is not capable of understanding the questions;
2. The program participant requests that a proxy complete the interview for them; or
3. A family member indicates that the program participant cannot complete the interview him or herself.

In each situation, you should first attempt to conduct the interview with the program participant rather than a proxy if at all possible. Second, you can offer the option of assisted interviews in which a family member or friend helps the program participant to understand the question or accommodate concerns. As a last resort, you may interview a proxy on behalf of the

program participant. In each situation, gently encourage the program participant to attempt to complete as much of the interview possible him or herself.

The following guidelines should be used in determining whether a proxy interview should be allowed:

- a. The program participant wants to complete the interview, but you believe that the participant is not capable of understanding the questions:**
  - Try a few questions with the program participant to assess whether he or she will be capable of responding. If the respondent appears to understand the questions but takes a long time to answer them, this is okay and a proxy is probably not necessary. If the program participant does not seem to understand the questions or gives answers that don't seem relevant, seek a proxy.
  - Determine whether a language interpreter or other accommodation such as taking breaks would help the program participant complete the survey.
  - Ask if there is someone available who can help answer the questions, and if so, proceed with an assisted interview. Sometimes only some questions pose a problem for the respondent and so occasional assistance, rather than a proxy, will suffice. For example, a respondent may know details of his or her day-to-day life, but may not know whether the people who help him are paid. In this case another person may be able to answer this particular question.
  - If an assisted interview is not possible, ask the program participant if there is a person who is familiar with the program participant's day-to-day life and can proceed with a proxy interview on their behalf.
  
- b. The program participant insists that a proxy complete the interview for them even though you suspect the program participant is capable of completing it him or herself:**
  - First, gently encourage the program participant to try to answer the survey questions. You can tell the respondent that we want to hear what he or she has to say, that there are no right or wrong answers, and that his or her responses will help improve services to people like them.
  - You can offer to do the interview in short sessions so as not to tire the respondent.
  - If the respondent still feels uncomfortable, offer an assisted interview, in which the respondent answers the questions, but is able to seek help from others to better understand the questions.
  - If the program participant still does not want to participate, identify a person who is familiar with the program participant's day-to-day life and proceed with a proxy interview.
  
- c. A family member insists that the program participant cannot do the interview or would be adversely affected by it:**
  - Tell the family member it's important we hear from the program participant directly if at all possible. The family member can remain nearby while the interview is being conducted in case the program participant needs assistance.

- Ask the family member if they would be willing to assist the program participant in responding.
- If an assisted interview is not possible, proceed with a proxy interview with the family member.

## **2. Conducting a proxy interview**

If you determine that a proxy is necessary, it is important that you select a proxy who is familiar with the respondent's situation. Generally, the best approach is to ask the respondent him or herself if there is a person, such as a family member, who can fill that role:

- "Is there someone who could answer questions about your health and daily activities?"
- If the respondent is unable to identify someone, you might ask a caseworker if he or she can identify someone or if he or she can serve as a proxy.

When conducting the interview with a proxy, remember that:

- The objective is to obtain the program participant's point of view, not the proxy's point of view. You may need to instruct the proxy, "Please remember that when answering these questions you are responding on the program participant's behalf and should respond as much as possible from his or her point of view, even if your own opinions differ."
- The question language will need to be modified for proxy respondents (for example changing "you" to the program participant's name).
- Proxy interviews should not be conducted for program participants who have died.

**TESTING RESPONDENT TO DETERMINE IF PROXY IS NECESSARY**

Next, I will explain some facts about the survey. After I explain, I will ask you three questions so I can be sure my explanation was clear.

**Here's the first explanation.**

The survey asks about [health, daily activities and any jobs you might have].

Please tell me in your own words what the survey is about. (Repeat **once**)

**Here is the next explanation.**

Taking part in the survey is completely voluntary. Completely voluntary means you can choose whether or not to take part. If you decide to take part, you can refuse to answer any questions you do not like and you can stop the interview at any time you choose. Whether you choose to take part or not, your [benefits/whatever it is they're receiving] will not be affected in any way. When I say your participation is completely voluntary, what does that mean to you? (Repeat **once**)

(Examples of accurate answers are: I can decide to take part or not to take part. I can refuse to take part if I want. I don't have to do this. I can do this if I want. No one will take away my benefits if I refuse; etc.)

**Here's the last explanation.**

All your answers will be kept confidential and use only for the research purposes of the study.

When I say that your answers will be kept confidential, what does that mean to you? (Repeat **once**)

(Examples of accurate answers are: My answers will be secret. Only researchers will see what I said. What I say will be kept private. It will only be used for research; etc.)

**RESULTS:**

**PARTICIPANT OR PROXY FAILS COGNITIVE TEST. FIND A PROXY/ANOTHER PROXY:** Thank you. Our study rules say that we need to find someone who can help answer the survey questions. Is there someone there who could answer questions about [participant's] health, daily activities and any jobs [he/she] might have?