

## Attachment 4 – Telephone Screening Script – Respondent recruited from newspaper advertisement/flyer/CCQDER database

Form Approved  
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### Sample screening script for respondent contact by Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) Staff for Phase 1 of Development and Cognitive Evaluation of Questions to Identify People with Intellectual and Developmental Disabilities in Point of Care Settings recruited through newspaper advertisement/flyer/email

Dial respondent's telephone number [hereafter referred to as *R*] as indicated on CCQDER voice mail system.

**Note: Respondents will be directed to indicate on the voicemail recording if they are calling in for themselves or if they are a caregiver/LAR calling in for someone else.**

**Note: Speak only to *R* (the person who called). If the number is answered by voice mail, call back at another time or say, "Hello, this is [NAME] from the National Center for Health Statistics. I am returning your call. You may call me back at [phone number] when you are free. Thank you."**

**CCQDER Staff:** Good morning/afternoon, may I speak to (name)?

**If *R* is not available or not at home, say, "Thank you" and try again at another time.**

**If the person who answered the phone (NOT *R*) asks, "Who is calling?" or "What's this about?" say, "I am returning their call to me. I'll try to reach them at another time.**

**If *R* has been successfully contacted and ...**

**If *R* called in for themselves, go to Self-Report Intro**

**If *R* is a caregiver calling for someone else, go to Proxy Intro**

**Recruiter note:** Invite proxy for separate interview if proxy eligibility has been met and with *Rs* permission (Reference Attachment 1).

## **Self-Report Intro:**

**\*\*\*NOTE: If, at any time during the screening call, R's consent capacity is in question, finish with exit script 1**

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...Hello, my name is [CCQDER Staff's name]. I am calling from the National Center for Health Statistics. [You may remember that you / Name of proxy] [responded to an [advertisement/flyer/email] we [placed/sent] [looking for/about adults to take part in a research study about health / looking for/about adults who have difficulties doing things in everyday life, like learning new things, solving problems, and making decisions]. Is this a safe time to talk? If you are driving, I will call you back. I can also call you back if you are too busy.

**Wait for acknowledgment, such as, "This is a safe time to talk."**

**If not a good time to talk, schedule a time to call back.**

**If good time to talk, continue to self-report screener**

## **Self-report Screener**

If proxy report called in response to advertisement/flyer/email on behalf of person with IDD or person with IDD took part in previous rounds go to Q2.

1. **Where did you see our advertisement/flyer?** \_\_\_\_\_

2. **How old are you?** [If under age 18, go to exit script 2] \_\_\_\_\_

3. **What is your gender?**

Male    Female    Other \_\_\_\_\_    Prefer not to say \_\_\_\_\_

4. **What state do you live in?** \_\_\_\_\_

5. **Has a doctor or other health professional ever told you that you have an intellectual or developmental disability?**

- Yes
- No

If Yes,

**Were you told you had an intellectual disability?**

- Yes, (specify disability/disabilities: \_\_\_\_\_)
- No, (specify disability/disabilities: \_\_\_\_\_)

If necessary,

6. **Has a doctor or other health professional ever told you that you have Autism, Asperger's disorder, pervasive developmental disorder, or autism spectrum disorder?**

- Yes
- No

7. **Has a doctor or other health professional ever told you that you have Cerebral Palsy?**

- Yes
- No

**Recruiter:** If Autism or CP, establish primary diagnosis if possible and whether with or without ID.

**8a. How much help do you need to do daily tasks like washing all over, dressing, and cooking food?**

- None
- Some
- A lot

**8b. How much help do you need to do daily activities like making appointments, using money, or shopping?**

- None
- Some
- A lot

**Recruiter:** Code severity based on support needed for daily living (8a and 8b responses<sup>1</sup>)

- Mild
- Moderate
- Severe

9. FOR INTERVIEWS TO BE CONDUCTED ONSITE AT NCHS-- **Are you a U.S. citizen?** [If No, go to exit script 3]

- Yes
- No

**10. What is the highest level of school you have completed?**

Less than High School (No Diploma or GED)  
High School Diploma or GED  
Associate Degree (Includes occupational, technical, or vocational program)  
Bachelor's Degree  
Graduate Degree

**11. Are you Spanish, Hispanic or Latino?**

Yes  
No

**12. What race or races do you consider yourself to be? You may indicate more than one race.**

American Indian or Alaska Native  
Asian  
Black or African American  
Native Hawaiian or Other Pacific Islander  
White

[If the recruitment needs for certain demographic groups have been achieved, go to exit script 4]. Otherwise continue.

### **Self-Report Entry Script:**

...Based on your answers to the questions so far, we would like you to take part in our study. For this study we'd like you to [come here to the National Center for Health Statistics in Hyattsville, Maryland/ agreed mutual location/ use a computer, tablet, or cellphone to have a video call via [Zoom]] with an interviewer who works at the National Center for Health Statistics (NCHS). Someone from NCHS will walk you through the process of downloading and setting up [Zoom] on your device. During the interview, the interviewer will talk with you about your health and how easy or hard it is for you to do things in everyday life, like learning new things, solving problems, and making decisions. The discussion that you have with our interviewer will help us to improve the data collected by public health systems which will help make sure that all people with disabilities are counted and that resources are allocated fairly.

You will receive \$50 for taking part. NCHS secures all information we collect, process, and store on our systems as required by Federal regulations, Executive Orders, and NCHS confidentiality statutes. [However, NCHS cannot secure

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<sup>1</sup> Questions 8a and 8b adapted from the National Core Indicators Survey of Adults ([National Core Indicators®-IDD - Nasddds](#))

and protect your personal computing devices, such as personal computer or smartphones, used to complete the NCHS interview.] With your permission, we would like to record the interview. The recording is a record of our discussion and helps the interviewer to concentrate on what you say rather than take detailed notes. Do you give permission to have your interview video recorded? *Yes/No* **[If no, go to exit script 5. At a minimum videorecording is essential for this project].**

Do you have any questions at this point? *Pause to answer questions.* If (not/you have no other questions), then let's get you on the schedule, ok? **[If respondent with IDD and in-person interview:** [Would you like to bring someone with you to the interview or do you want to come by yourself?]

We will be interviewing (Day, Month/Date) through (Day, Month/Date) from 8 a.m. to 6 p.m. Looking at your schedule, when would you be available to participate? **[If respondent does not manage own schedule ask if the respondent/ you can speak to the person who does and explain who you are and why you are asking]** *Schedule.* **[If date/times not available go to exit script 6.]**

**If Virtual:** After we talk today, you will be sent a confirmation email with the date and time of your interview. [We can also send the confirmation email to (support person previously specified)]. *Obtain email addresses.* Attached with the confirmation email will be a consent/assent form. In order to take part in the study you must read the entire consent/assent form. The consent/assent form tells you about the study and what you will be asked to do. If you have any questions about confidentiality, identity protection, procedures or other topics related to the study please contact me [name] at [phone number/email] any time before your interview.

**[If remuneration is cash]** What is your mailing address? We will use this address to send you \$50 cash via FedEx after the completion of the interview. Packages typically take 5 business days to arrive. **[If R unsure of mailing address ask their permission to speak with a support person for that information].**

**[If remuneration is an electronic gift cards]** After your interview, we will email you the activation code for your \$50 electronic gift card with a "thank you" letter. The email will be sent right after your interview, and you will be able to use your electronic gift card immediately after activation. **[If R unsure of email address ask their permission to speak with a support person for that information].**

**If virtual:** Do you have 5 minutes right now to set up [Zoom] on the device, you will be using for the interview? If not, we can schedule another time to do it prior to the interview. **[If R needs help setting up the conference call on their device ask their permission to talk with a support person about the set-up procedures.]**

**If virtual:** We ask that you be in a quiet, private space, alone with minimal distractions during your interview. To protect your identity, we ask that no photos or personal identifiable items be visible during the interview. To minimize movement and distractions during the interview please place your device on a stable surface.

May I just check, do you use any special communication aids or hearing aids? *Yes (Specify) /No*

A reminder call will be made to you a few days in advance. Should you have any questions or need to change your appointment, please feel free to contact me [name] at [phone number].

Thank you for responding to our ad, and I look forward to seeing you here at (DATE/TIME) *Get respondent to cite date & time if possible.*

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**Exit script 1:** Do you have a family member or any other person you would like to bring with you to the interview?

- **If yes:** Is it OK if I contact that person to give them information about our study and confirm your eligibility? *If R agrees, obtain contact information and skip to LAR Intro. If R doesn't agree, continue to "If no or not sure" bullet point below.*
- **If no or not sure:** That's ok. Can someone from my office call you back to talk more about the details of the study? *If yes, confirm contact information and notify staff Interviewer, who will call to conduct formal assessment of consent capacity. If no, We appreciate your call and thank you for your interest in our study.*

**Exit script 2:** I'm sorry, you have to be 18 years of age or older take part in this study and therefore we won't be able to interview you at this time. We appreciate your call and thank you for your interest in our study.

**Exit Script 3:** I'm sorry, all Federal Government facilities require screening procedures for non-U.S. citizens. This process can take more than 30 days. Unfortunately, our study has to be completed before your screening process would be complete. Would you be agreeable to having your interview conducted at an offsite location? *If yes*, discuss off-site interviewing locations. *If no*, Would it be okay if I added your name, telephone number, age, educational level, ethnicity and race to our database so that I can contact you about other studies coming up in the future? Your information will be kept for up to 5 years and you can decide at any time to be removed from our database. Email [recruitmentteam@cdc.gov](mailto:recruitmentteam@cdc.gov) to request removal. *If yes*, add to database. *If no*: OK, thank you for your time. Your name and any information you gave me will not be added to our database.

**Exit script 4:** Based upon your answers, it seems that we may already have a number of volunteers with very similar answers to yours. At this point we need to talk with people with some different characteristics. However, if we have cancellations or other slots open up, I may wish to call you back. Would it be okay if I kept your name, telephone number, and the information you provided in response to the eligibility questions until the end of this study? *If yes*, make notation. *If no*, Would it be okay if I added your name, telephone number, age, educational level, ethnicity and race to our database so that I can contact you about other studies coming up in the future? Your information will be kept for up to 5 years and you can decide at any time to be removed from our database. Email [recruitmentteam@cdc.gov](mailto:recruitmentteam@cdc.gov) to request removal. *If yes*, add to database. *If no*: OK, thank you for your time. Your name and any information you gave me will not be added to our database.

**Exit script 5:** I'm sorry, willingness to be videorecorded is required in order to take part in this study and therefore we won't be able to use you at this time. Would it be okay if I added your name, telephone number, age, educational level, and race to our database so that I can contact you about other studies coming up in the future? Your information will be kept for up to 5 years and you can decide at any time to be removed from our database. Email [recruitmentteam@cdc.gov](mailto:recruitmentteam@cdc.gov) to request removal. *If yes*, add to database. *If no*: OK, thank you for your time. Your name and any information you gave me will not be added to our database.

**Exit script 6:** I see...ok, we were hoping to complete this particular study between (Month/Date) and (Month/Date), so it looks like we won't be able to schedule you at this time. Would it be okay if I added your name, telephone number, age, educational level, ethnicity and race to our database so that I can contact you about other studies coming up in the future? Your information will be kept for up to 5 years and you can decide at any time to be removed from our database. Email [recruitmentteam@cdc.gov](mailto:recruitmentteam@cdc.gov) to request removal. *If yes*, add to database. *If no*: OK, thank you for your time. Your name and any information you gave me will not be added to our database.

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### **LAR Intro:**

“...Hello, my name is [CCQDER Staff’s name]. I am calling from the National Center for Health Statistics. I’m calling because a person under your care, [*name of adult with IDD*], is interested in a survey research study we are conducting. Are you his/her legally authorized representative? *If yes, continue. If no or not sure, Go to exit script 1.* Is this a safe time to talk? If you are driving, I will call you back. I can also call you back if you are too busy.”

**Wait for acknowledgment, such as, “This is a safe time to talk.”**

“...In order to determine if the person under your care is eligible for our study, I’ll need a few minutes of your time to ask some background questions. Answering these questions is completely voluntary and takes about 5 minutes. We are required by law to use the information you provide for statistical research only and to keep it confidential. The law prohibits us from giving anyone any information that may identify you or the person you care for without your consent. Is this a good time to ask the questions or should I call back later? “

**If not a good time to talk, schedule a time to call back.**

**If good time to talk, continue to LAR screener**

### **LAR Screener**

1. **How old is the person under your care?** [If under age 18, go to exit script 2] \_\_\_\_\_

2. **What is the gender of the person under your care?**

Male    Female    Other \_\_\_\_\_    Prefer not to say \_\_\_\_\_

3. **What state does the person under your care live in?** \_\_\_\_\_

4. **Has a doctor or other health professional ever told the person under your care that he/she has an intellectual or developmental disability?**

- Yes
- No

If Yes,

**Was he/she told he/she had an intellectual disability?**

- Yes, (*specify disability/disabilities:* \_\_\_\_\_)
- No, (*specify disability/disabilities:* \_\_\_\_\_)

If necessary,

5. **Has a doctor or other health professional ever told the person under your care that he/she Autism, Asperger's disorder, pervasive developmental disorder, or autism spectrum disorder?**

- Yes
- No

6. **Has a doctor or other health professional ever told you that you have Cerebral Palsy?**

- Yes
- No

**Recruiter:** If Autism or CP, establish primary diagnosis if possible and whether with or without ID.

**7a. How much help does the person under your care need to do daily tasks like washing all over, dressing, and cooking food?**

- None
- Some
- A lot

**7b. How much help does the person under your care need to do daily activities like making appointments, using money, or shopping?**

- None
- Some
- A lot

**Recruiter:** Code severity based on support needed for daily living (7a and 7b responses<sup>2</sup>)

- Mild
- Moderate
- Severe

**8. Are you willing and able to accompany him/her to an interview?**

- No **[Go to exit script 3]**
- Yes

**9. [If virtual] Are you willing to be available to help set up the interview via Zoom?**

- Yes
- No, but someone else will help with set up
- No, no one will be available to help with set up **[go to exit script 3a]**

**[If respondent has not met one of the eligibility criteria go to exit script 4]**

**10. FOR INTERVIEWS TO BE CONDUCTED ONSITE AT NCHS—Is he/she and are you a U.S. citizen? [If No, go to exit script 5]**

- Yes
- No

**11. What is the highest level of school he/she has completed?**

Less than High School (No Diploma or GED)  
High School Diploma or GED  
Associate Degree (Includes occupational, technical, or vocational program)  
Bachelor's Degree  
Graduate Degree

**12. Is he/she Spanish, Hispanic or Latino?**

Yes  
No

**13. What race or races does he/she consider himself/herself to be? You may indicate more than one race.**

American Indian or Alaska Native  
Asian  
Black or African American  
Native Hawaiian or Other Pacific Islander  
White

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<sup>2</sup> Questions 8a and 8b adapted from the National Core Indicators Survey of Adults ([National Core Indicators®-IDD - Nasddds](#))

**[If the recruitment needs for certain demographic groups have been achieved, go to exit script 6]. Otherwise continue.**

**LAR Entry Script:**

...Based on your answers to the questions so far, we would like to invite him/her to take part in our study. For this study we'd like him/her to [come here to the National Center for Health Statistics in Hyattsville, Maryland/agreed mutual location/ use a computer, tablet, or cellphone to have a video call via [Zoom]] with an interviewer who works at the National Center for Health Statistics (NCHS). Someone from NCHS will walk you through the process of downloading and setting up [Zoom] on your device.] An interviewer will ask him/her a variety of questions about difficulties he/she may have doing day-to-day activities, like learning new things, solving problems, and making decisions. Then the interviewer will ask him/her to explain what he/she was thinking as he/she answered the questions. The interviewer will also ask about his/her opinions of the questions. His/her answers will help us find out if the survey questions will be easy for other people to answer. Everything he/she says will be kept private, and he/she doesn't have to answer any question he/she doesn't want to. With your permission, we would like to record the interview. The recording is a record of what we asked and what he/she said about the questions and helps the interviewer to concentrate on what you say rather than take detailed notes. Do you give permission to have his/her interview video recorded? *Yes/No*. **[If no, go to exit script 7. At a minimum video recording is essential for this project].**

We would also like to invite you to complete a similar interview, answering the questions in reference to the person under your care. The interview will take place at the same time as his/her interview and you both will be compensated \$50 each. Are you interested in participating in your own interview? *Yes/No*

*If Yes: Great!*

*If No: That's ok. We would still like for him/her to participate and for you to accompany him/her to the interview.*

Do you have any questions at this point? *Pause to answer questions*. If (not/you have no other questions), then let's get you on the schedule, ok? We will be interviewing (Day, Month/Date) through (Day, Month/Date) from 8 a.m. to 6 p.m. Looking at your schedule, when would you both/he/she be available to participate? *Schedule*. **[If date/times not available go to exit script 8.]**

After we talk today, we will send you a confirmation email with the date and time of the interview. Attached with the confirmation email will be a consent form for you to complete giving your permission for the person in your care to take part in the interview [and a consent form for your interview for you to also sign]. In order for the person in your care to take part in the study you must read the entire consent form. You must sign and return the consent form before the person in your care is scheduled for interview. You will also be asked to complete a data collection form for the person in your care. The forms can be signed and completed electronically. The consent form tells you about the study and what the person in your care will be asked to do. If you have any questions about confidentiality, identity protection, procedures or other topics related to the study, please contact me [YOUR NAME] at [YOUR PHONE NUMBER / EMAIL] any time before the interview. An assent form will also be sent for the person in your care to read. The person in your care does not need to sign or complete anything in advance of the interview. The interviewer will explain the assent form to the person in your care at the start of the interview. As an added protection, a witness will also be present for the assent at the time of the interview.

***If virtual:*** What is the email address of the person in your care? *Obtain email address and that of the LAR if taking part in own interview*. We will use the address to send the person in your care/you a \$50 electronic gift card after completion of the interview. Packages typically take 5 business days to arrive.

***If virtual:*** Do you have 5 minutes right now to set up [Zoom] on the device(s) you will be using for the interview? If not, we can schedule another time to do it prior to the interview. **[If R needs help setting up the conference call on their device ask their permission to talk with a support person about the setup procedures.]**

***If virtual:*** We ask that you/the person in your care be in a quiet, private space, alone with minimal distractions during the interview. To protect identity, we ask that no photos or personal identifiable items be visible during the interview. To minimize movement and distractions during the interview please place the device on a stable surface.

May I just check, does the person in your care use any special communication aids or hearing aids? *Yes (Specify) /No*



A reminder call will be made to you a few days in advance. Should you have any questions or need to change your appointment, please feel free to contact me [name] at [phone number]. Thank you for responding to our ad, and I look forward to seeing you at (DATE/TIME) *Get respondent to cite date & time if possible.*

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**Exit script 1:** I'm sorry, we'll need to speak with a legally authorized representative before we can go any further. Can you put me in touch with their legal authorized representative? *If no*, We won't be able to invite him/her to participate in our study at this time. We appreciate your call and thank you for your interest in our study.

**Exit script 2:** I'm sorry, he/she has to be 18 years of age or older take part in this study and therefore we won't be able to invite him/her to participate in our study at this time. We appreciate your call and thank you for your interest in our study.

**Exit script 3:** In order for him/her to participate in the study, we need you to read and sign a consent form. The consent form tells you about the study, and what he/she is being asked to do as part of the study. Would you like me to send the forms through the mail/email? I will need the completed forms back before the scheduled interview. You can send back the completed forms by mail or email [or deliver in person]. [You may also send the completed forms back through [name of respondent with IDD] in a sealed envelope provided by us. However, if you send the completed forms back through him/her, you MUST be available by phone to verify that you have given permission for him/her to participate in the study] If the completed forms are not received before the start of the interview, and if the completed forms were returned by [name of respondent with IDD] and you cannot confirm permission for him/her to participate, he/she will not be allowed to participate in the study and will not receive the \$50. **[Record method of getting the forms to the LAR:].**

**Exit script 3a:** In order for him/her to participate in the study, he/she will need to set up Zoom for the interview, so we are unable to schedule the interview at this time. We appreciate your call and thank you for your interest in our study.

**Exit script 4:** I'm sorry, he/she has not met one of the eligibility requirements for this particular study. Thank you for your time.

**Exit Script 5:** I'm sorry, all Federal Government facilities require screening procedures for non-U.S. citizens. This process can take more than 30 days. Unfortunately, our study has to be completed before this screening process would be complete. Would you be agreeable to having his/her interview conducted at an offsite location? *If yes*, discuss off-site interviewing locations. *If no*, Thank you for your time.

**Exit script 6:** Based upon your answers, it seems that we may already have a number of volunteers with very similar answers to yours. At this point we need to talk with people with some different characteristics. However, if we have cancellations or other slots open up, I may wish to call you back. Would it be okay if I kept your name, telephone number, and the information you provided in response to the eligibility questions until the end of this study? *If yes*, make notation. *If no*, OK, thank you for your time.

**Exit script 7:** I'm sorry, willingness to be videorecorded is required in order to take part in this study and therefore we won't be able to invite him/her to participate in our study at this time. Thank you for your time.

**Exit script 8:** I see...ok, we were hoping to complete this particular study between (Month/Date) and (Month/Date), so it looks like we won't be able to schedule you at this time. Thank you for your time.

**Proxy Intro:**

"...Hello, my name is [CCQDER Staff's name]. I am calling from the National Center for Health Statistics. You may remember that you responded to an [advertisement/flyer/email / took part in an interview [DATE]] aimed at caregivers of an adult with an intellectual or developmental disability. Is this a safe time to talk? If you are driving, I will call you back. I can also call you back if you are too busy."

**Wait for acknowledgment, such as, "This is a safe time to talk."**

We are interested in talking with the caretakers of adults with an intellectual or developmental disability about the difficulties the person under their care has with day-to-day activities, like learning new things, solving problems, and making decisions. We would also like to talk separately with the person under your care about his/her own experiences.

In order to determine if you and the person under your care meet the eligibility criteria for our study, I'll need a few minutes of your time to ask some background questions. I will also need to speak with the person in your care to invite him or her to complete a similar interview and ask him/her some background questions. We will only be able to interview you if the person in your care qualifies and agrees to take part in the study. Answering these questions is completely voluntary. We are required by law to use the information provided for statistical research only and to keep it confidential. The law prohibits us from giving anyone any information that may identify you or the person you care for without your consent and that of the person in your care. Is this a good time to ask the questions or should I call back later? “

**If not a good time to talk, schedule a time to call back.**

**If good time to talk, continue**

Your interview and that of the person in your care will take place separately. You both will be compensated \$50 each. Do you think he/she would be willing and able to participate in his/her own interview? *Yes/No*

*If No:* go to exit script 5.

*If Yes:* Continue to Proxy-report Screener

### **Proxy-report Screener**

Can you put me in touch with the person in your care so I can do a brief screening and give him/her information about the interview? (*Collect contact information.*) If after speaking with the person in your care he/she does not meet our eligibility criteria I will not be able to schedule an interview separately with you.

**If proxy-report says that the person in their care will have difficulty providing consent and will require assent – continue with Screener, else continue to Self-report Screener for person with IDD.**

**Ask the following of proxy respondents if the person in their care was unable to provide any of the information.**

**1. What is the gender of the person under your care?**

Male    Female    Other \_\_\_\_\_    Prefer not to say \_\_\_\_\_

**2. What state does the person under your care live in? \_\_\_\_\_ \**

**3. Has a doctor or other health professional ever told the person under your care that he/she has an intellectual or developmental disability?**

- Yes
- No

If Yes,

**Was he/she told he/she had an intellectual disability?**

- Yes, (*specify disability/disabilities:* \_\_\_\_\_)
- No, (*specify disability/disabilities:* \_\_\_\_\_)

If necessary,

**4. Has a doctor or other health professional ever told the person under your care that he/she Autism, Asperger's disorder, pervasive developmental disorder, or autism spectrum disorder?**

- Yes
- No

**5. Has a doctor or other health professional ever told the person under your care that he/she has Cerebral Palsy?**

- Yes
- No

**Recruiter:** If Autism or CP, establish primary diagnosis if possible and whether with or without ID.

**6a. How much help does the person under your care need to do daily tasks like washing all over, dressing, and cooking food?**

- None
- Some
- A lot

**6b. How much help does the person under your care need to do daily activities like making appointments, using money, or shopping?**

- None
- Some
- A lot

**Recruiter:** Code severity based on support needed for daily living (6a and 6b responses<sup>3</sup>)

- Mild
- Moderate
- Severe

**[If respondent has not met one of the eligibility criteria go to exit script 2]**

**7. FOR INTERVIEWS TO BE CONDUCTED ONSITE AT NCHS—Are you a U.S. citizen? [If No, go to exit script 3]**

- Yes
- No

**7a. Is the person in your care a U.S. citizen? [If No, go to exit script 3]**

- Yes
- No

**8. What is the highest level of school he/she has completed?**

Less than High School (No Diploma or GED)  
High School Diploma or GED  
Associate Degree (Includes occupational, technical, or vocational program)  
Bachelor's Degree  
Graduate Degree

**9. Is he/she Spanish, Hispanic or Latino?**

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<sup>3</sup> Questions 8a and 8b adapted from the National Core Indicators Survey of Adults ([National Core Indicators®-IDD - Nasddds](#))

Yes  
No

10. What race or races does he/she consider himself/herself to be? You may indicate more than one race.
- American Indian or Alaska Native
  - Asian
  - Black or African American
  - Native Hawaiian or Other Pacific Islander
  - White

**If the recruitment needs for certain demographic groups have been achieved, go to exit script 4. Otherwise continue.**

**Proxy Entry Script:**

...Based on your answers [and those of the person under your care] to the questions so far, we would like you both to take part in our study.

**In-person:** For this study we'd like you to come here to the National Center for Health Statistics in Hyattsville, Maryland/agreed mutual location. An interviewer will ask you a variety of questions about difficulties he/she may have doing day-to-day activities, like learning new things, solving problems, and making decisions. Then the interviewer will ask you to explain what you were thinking as you answered the questions. Your answers will help us find out how people understand and answer the survey questions and if the survey questions will be easy for other people to answer. Everything you say will be kept private. With your permission, we would like to record the interview. The recording is a record of what we asked and what you said about the question and helps the interviewer to concentrate on what you say rather than take detailed notes. Do you give permission to have your interview video recorded? *Yes/No.* **[If no, go to exit script 6. At a minimum videorecording is essential for this project].**

**Virtual:** For this study we'd like you to use a computer, tablet, or cellphone to have a video call via [Zoom] with an interviewer that works at the National Center for Health Statistics (NCHS). Do you have more than one device such that both the interview with yourself and that of the person in your care can be conducted at the same time? *Record response Yes/No. If not schedule for different times.* Someone from NCHS will walk you through the process of downloading and setting up [Zoom] on your device. If the person in your care needs help setting up their device, we ask that you be on hand to help with that.

During the interview, the interviewer will ask you a variety of questions about difficulties the person in your care may have doing day-to-day activities, like learning new things, solving problems, and making decisions. Then the interviewer will ask you to explain what you were thinking as you answered the questions. Your answers will help us to find out how people understand and answer the survey questions and if the survey questions will be easy for other people to answer. NCHS secures all information we collect, process and store on our systems as required by Federal regulations, Executive Orders, and NCHS confidentiality statutes. However, NCHS cannot secure and protect your personal computing devices, such as personal computer or smart phones, used to complete the NCHS interview.

With your permission, we would like to video record your interview. The recording is a record of our discussion and helps the interviewer to concentrate on what you say rather than take detailed notes. Do you give permission to have your interview recorded? *Yes/No* **[If no, go to exit script 6. At a minimum video recording is essential for this project].**

After the interview we would be interested in your feedback about the interview in order to improve our procedures. Would you be willing to participate in a brief, 5-minute follow-up phone call after your interview? You do not have to agree to this in order to be eligible to take part in the interview. *Note response: Yes or No.*

**In-person and virtual:** Do you have any questions at this point? *Pause to answer questions.* If (not/you have no other questions), then let's get you on the schedule, ok? We will be interviewing (Day, Month/Date) through (Day, Month/Date) from 8 a.m. to 6 p.m. Looking at your schedules, when would you be available to participate? *Schedule.* **[If date/times not available go to exit script 7.]** *If proxy respondent agreed to follow-up discussion, schedule that call as well. If not, move to next paragraph.* We will be conducting follow-up calls from (Day, Month/Date) through (Day, Month/Date) from (time to time). Looking at your schedule for those days, when would you be available to participate?

*Schedule. If date/time not available for follow-up call, the respondent can still participate in the interview without participating in a follow-up call.*

May I just check, does the person in your care use any special communication aids or hearing aids? *Yes (Specify) /No*

What is your email address? We will use this address to send your \$50 e-gift card after the completion of the interview. Packages typically take 5 business days to arrive. ***If proxy is also LAR check mailing address for person under their care.***

Do you have 5 minutes right now to set up [Zoom] on the device you will be using for the interview? And, if necessary for the person in your care as well? If not, we can schedule another time to do it prior to the interview.

We ask that you be in a quiet space, alone with minimal distractions during the interview. To protect your identity, we ask that no photos or personally identifiable materials are visible.

A reminder call will be made to you a few days in advance. Should you have any questions or need to change your appointment, please feel free to contact me [name] at [phone number]. Thank you for responding to our ad, and I look forward to seeing you at (DATE/TIME) *Get respondent to cite date & time if possible.*

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**Exit script 1:** I'm sorry, he/she has to be 18 years of age or older to meet eligibility criteria for this study and therefore you won't be able to participate at this time. We appreciate your call and thank you for your interest in our study.

**Exit script 2:** I'm sorry, he/she has not met one of the eligibility requirements for this particular study. However, I would like to put his/her name and the information you gave me into our database so that I can contact you about other studies coming up in the future. Your information will be kept for up to 5 years and you can decide at any time to be removed from our database. Email [recruitmentteam@cdc.gov](mailto:recruitmentteam@cdc.gov) to request removal. If yes, add to database. If no: OK, thank you for your time. Your name and any information you gave me will not be added to our database.

**Exit Script 3:** I'm sorry, all Federal Government facilities require screening procedures for non-U.S. citizens. This process can take more than 30 days. Unfortunately, our study has to be completed before this screening process would be complete. Would you be agreeable to having your interview conducted at an offsite location? *If yes*, discuss off-site interviewing locations. *If no*, Would it be okay if I added your telephone number and his/her name, age, educational level, ethnicity and race to our database so that I can contact you about other studies coming up in the future? Your information will be kept for up to 5 years and you can decide at any time to be removed from our database. Email [recruitmentteam@cdc.gov](mailto:recruitmentteam@cdc.gov) to request removal. If yes, add to database. If no: OK, thank you for your time. Your name and any information you gave me will not be added to our database.

**Exit script 4:** Based upon your answers, it seems that we may already have a number of volunteers with very similar answers to yours. At this point we need to talk with people with some different characteristics. However, if we have cancellations or other slots open up, I may wish to call you back. Would it be okay if I kept your name, telephone number, and the information you provided in response to the eligibility questions until the end of this study? Your information will be kept for up to 5 years and you can decide at any time to be removed from our database. Email [recruitmentteam@cdc.gov](mailto:recruitmentteam@cdc.gov) to request removal. If yes, add to database. If no: OK, thank you for your time. Your name and any information you gave me will not be added to our database.

**Exit script 5:** At this time, we are only interviewing caretakers for those individuals with an intellectual or developmental disability who are also able to participate in a separate interview. Unfortunately, I will not be able to schedule an interview with you at this time. However, I would like to [add/keep] your name, age, education level and race [to/in] our database so that I can contact you about other studies coming up in the future. Is that OK? Your information will be kept for up to 5 years and you can decide at any time to be removed from our database. Email [recruitmentteam@cdc.gov](mailto:recruitmentteam@cdc.gov) to request removal. If yes, add to database. If no: OK, thank you for your time. Your name and any information you gave me will not be added to our database.

**Exit script 6:** I'm sorry, willingness to be videorecorded recorded is required in order to take part in this study and therefore we won't be able to use you at this time. Would it be okay if I added your name, telephone number, age, educational level, and race to our database so that I can contact you about other studies coming up in the future? Your information will be kept for up to 5 years and you can decide at any time to be removed from our database. Email [recruitmentteam@cdc.gov](mailto:recruitmentteam@cdc.gov) to request removal. If yes, add to database. If no: OK, thank you for your time. Your name and any information you gave me will not be added to our database.

**Exit script 7:** I see...ok, we were hoping to complete this particular study between (Month/Date) and (Month/Date), so it looks like we won't be able to schedule you at this time. Thank you for your time.