

## Attachment 1a: Questions to be cognitively tested in self-report interview

Form Approved  
OMB No. 0920-0222  
Exp. Date: 08/31/2021

Notice - CDC estimates the average public reporting burden for this collection of information as 55 minutes per response, including the time for reviewing instructions, searching existing data/information sources, gathering and maintaining the data/information needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Information Collection Review Office, 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-0222).

Assurance of confidentiality - We take your privacy very seriously. All information that relates to or describes identifiable characteristics of individuals, a practice, or an establishment will be used only for statistical purposes. NCHS staff, contractors, and agents will not disclose or release responses in identifiable form without the consent of the individual or establishment in accordance with section 308(d) of the Public Health Service Act (42 U.S.C. 242m(d)) and the Confidential Information Protection and Statistical Efficiency Act of 2002 (CIPSEA, Title 5 of Public Law 107-347).

These questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses? Would you say:
  - a. No - no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
2. Do you have difficulty hearing, even if using a hearing aid? Would you say:
  - a. No- no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
3. Do you have difficulty walking or climbing steps? Would you say:
  - a. No- no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
4. Do you have difficulty remembering or concentrating? Would you say:
  - a. No – no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
5. Do you have difficulty with self-care such as washing all over or dressing? Would you say:
  - a. No – no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
6. Using your usual language, do you have difficulty communicating, for example understanding or being understood? Would you say:
  - a. No – no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
7. Because of a physical, mental, or emotional problem, do you have difficulty doing errands alone such as visiting a doctor’s office or shopping? Would you say:
  - a. No - no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
8. Do you have difficulty learning how to do things most people your age can learn? Would you say:
  - a. No – no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all

➔ *SKIP (If answered “a.” to ALL QUESTIONS above, skip to Question 10; otherwise, continue)*

### Age of onset

9. You said that you had difficulty doing \_\_ [fill from Q1 – Q8, if answered anything other than “a. No – no difficulty”] \_\_, did any of this happen before you turned 22?
  - a. No, all this happened after I turned 22
  - b. Yes, some of this happened before I turned 22

## Learning

10. Do you have difficulty understanding and using information like following directions? Would you say:  
a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
11. Do you have difficulty analyzing problems and finding solutions? Would you say:  
a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
12. Did you have difficulty learning in school or learning how to read or write? Would you say:  
a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all

## Self-direction and Relationships

13. Do you have difficulty making friends? Would you say:  
a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
14. Do you have difficulty dealing with people you do not know well? Would you say:  
a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
15. Do you have difficulty getting along with people who are close to you?  
a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
16. Do you have difficulty controlling your behavior when you are together with other people?  
a. All the time    b. Most of the time    c. Sometimes    d. Rarely    e. Never
17. How often are you able to make your own decisions about important things in your life, for example, where to live, what to eat, and how to spend your free time? Would you say:  
a. All the time    b. Most of the time    c. Sometimes    d. Rarely    e. Never

## Attachment 1b: Questions to be cognitively tested in proxy interview

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These questions ask about difficulties     (name of adult with IDD)     may have doing certain activities because of a HEALTH PROBLEM.

1. Does he/she have difficulty seeing, even if wearing glasses? Would you say:  
a. No - no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
  2. Does he/she have difficulty hearing, even if using a hearing aid? Would you say:  
a. No- no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
  3. Does he/she have difficulty walking or climbing steps? Would you say:  
a. No- no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
  4. Does he/she have difficulty remembering or concentrating? Would you say:  
a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
  5. Does he/she have difficulty with self-care such as washing all over or dressing? Would you say:  
a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
  6. Using his/her usual language, does he/she have difficulty communicating, for example understanding or being understood? Would you say:  
a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
  7. Because of a physical, mental, or emotional problem, does he/she have difficulty doing errands alone such as visiting a doctor’s office or shopping? Would you say:  
a. No - no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
  8. Does he/she have difficulty learning how to do things most people his/her age can learn? Would you say:  
a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
- ➔ *SKIP (If answered “a.” to ALL QUESTIONS above, skip to Question 10; otherwise, continue)*

### Age of onset

9. You said that he/she had difficulty doing     [fill from Q1 – Q8, if answered anything other than “a. No – no difficulty”]    , did any of this happen before he/she turned 22?  
a. No, all this happened after he/she turned 22 b. Yes, some of this happened before he/she turned 22

### Learning

10. Does he/she have difficulty understanding and using information like following directions? Would you say:  
a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
11. Does he/she have difficulty analyzing problems and finding solutions? Would you say:  
a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
12. Did he/she have difficulty learning in school or learning how to read or write? Would you say:  
a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all

### Self-direction and Relationships

13. Does he/she have difficulty making friends? Would you say:  
a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
14. Does he/she have difficulty dealing with people he/she does not know well? Would you say:  
a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
15. Does he/she have difficulty getting along with people who are close to him/her?  
a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
16. Does he/she have difficulty controlling his/her behavior when he/she is together with other people?  
a. All the time b. Most of the time c. Sometimes d. Rarely e. Never
17. How often is he/she able to make his/her own decisions about important things in his/her life, for example, where to live, what to eat, and how to spend his/her free time? Would you say:  
a. All the time b. Most of the time c. Sometimes d. Rarely e. Never