

Notice - CDC estimates the average public reporting burden for this collection of information as 75 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 H21-8, 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 or CIPSEA (44 U.S.C. 3561-3583). In accordance with CIPSEA, every NCHS employee, contractor, and agent has taken an oath and is subject to a jail term of up to five years, a fine of up to \$250,000, or both if he or she willfully discloses ANY identifiable information about you. In addition to the above cited laws, NCHS complies with the Federal Cybersecurity Enhancement Act of 2015 (6 U.S.C. §§ 151 and 151 note) which protects Federal information systems from cybersecurity risks by screening their networks.

Development of Questions to include adults with Intellectual and Developmental Disabilities (ID/DD) in Point of Care Settings

For Interviewer Use Only

Qualitative exploratory research: Interviewer's guide. (Person with ID/DD)

Research Aim

To identify any additional functional difficulties or barriers to participation in day-to-day activities associated with ID/DD but not captured by domains of standard disability question sets, such as the Washington Group-Short Set and the American Community Survey questions on disability.

Research objectives

- To elicit a conversation to identify functioning that individuals with ID/DD could be identified from.
- To establish the way in which people with ID/DD, who take part in the study, best communicate.

Exploring:

- Day-to-day activities person with ID/DD has difficulty performing, level of difficulty & why.
- Barriers to participation in daily life and life opportunities.
- Level of support received and whether that support is sufficient.
- Main methods of communication.

The information from this study will be used to help develop a functional disability demographic checklist that can be used within a point of care setting to identify adults as having a disability, to be inclusive of adults with an intellectual and developmental disability (ID/DD). Ultimately, the checklist of items developed by this study will help to improve the capture of those with ID/DD in administrative data systems used for public health surveillance and allocation of resources.

Interviewers should focus on information needed to develop a functional difficulty checklist and obtain 'biographical fragments' where possible. Biographical fragments are small, focused sections of a person's life history – experiences learning in school or starting their first job, for instance, which will help interviewers to understand people's lives, and barriers and successes experienced.

1. Introduction and consent

- Check if respondent can see and hear interviewer clearly
- Introduce self and NCHS
- Explain/Reiterate:
 - Purpose of research
 - Nature and length of discussion
 - Voluntary and confidential nature of research
 - Confirm privacy
 - Transcription
 - Video and audio recording
- Start recording
 - Verbal consent to take part and record

2. Opening discussion

- Describe what's fun/enjoy/easy/hobby/likes/feel good
- Current/past member of club, organization, group
- *If needed*, description of a typical day

3. Difficulties / challenges in life

- Challenges/ problems/ dislikes /feel bad
- Current /past difficulties or challenges in day-to-day activities (e.g., Mobility, cognition, self-care, communication, other).
- Level of difficulty/changes over time
- Barriers to overcoming difficulty/problem
- Impact on life/daily living
- Comparison with others

4. Outlook on life

- Determine positive / negative outlook on life

5. Disability / impairment

- Knowledge / perception of disability / how describe
- Type of disability, if known
- How other people describe/ view /see disability
- Age of onset/ongoing difficulty

6. Household composition

- Living arrangements

Specific domains

7. Independent living

- Level of independence
- Help and support with day-to-day activities (aide or caretaker / special equipment)
- Ability to do errands alone
- What aspects does person need help with? (Physical/mental/emotional)
- Enough help? More help? Less help?
- Use of aids and equipment
- Barriers to independent living

8. Access to transportation (Mobility)

- Ability to drive
- Barriers to transportation use
- Ability to use public transportation
- Cost barriers/anxiety barriers/other barriers

9. Learning

- Academic vs. non-academic learning
- Type of school attended incl. special education classes / Qualifications obtained
- Barriers to learning / Literacy levels
- Feelings about school/difficulties at school
- Learning as an adult
- Adapting to change

10. Form of thought

- Following a process / doing things in the right order

11. Focused attention

- Easily distracted / difficulty concentrating

12. Interaction with others

- Barriers to interacting with other people
- Social isolation / not understanding social norms
- Attitudes
 - Nervous of strangers / untrusting of strangers / fearful of other people
- Self-expression
 - Ability to express feelings/needs to others
 - Receptiveness of others to feelings/needs of person with disability

13. Economic life

- Basic transactions – paying for things in grocery store, conceptualizing amounts
- Complex transactions – managing bank account, managing finances/paying bills

14. Employment opportunities

- Employment current/past
- Barriers to employment

- Feelings about jobs
- Employment support (e.g. job coach/training)

15. Communication

- Communication style preference
- Internet access/use

16. Ideas and suggestions

- From person being interviewed

17. Closing

- Signpost: discussion will be ending in 5 minutes
- End on a positive
- Invite participant to raise any other issues/share anything else/ ask any questions
- End interview discussion

Development of Questions to include adults with Intellectual and Developmental Disabilities (ID/DD) in Point of Care Settings

For Interviewer Use Only

Qualitative exploratory research: Interviewer's guide. (Close personal contact for person with ID/DD)

Research Aim

To identify any additional functional difficulties or barriers to participation in day-to-day activities associated with ID/DD but not captured by domains of standard disability questions sets such as the Washington Group-Short Set and the American Community Survey questions on disability.

Research objectives

- To elicit a conversation to identify functioning that individuals with ID/DD could be identified from.
- To establish the way in which people with ID/DD, who take part in the study, best communicate.

Exploring:

- Day-to-day activities person with ID/DD has difficulty performing, level of difficulty & why.
- Barriers to participation in daily life and life opportunities.
- Level of support received and whether that support is sufficient.
- Main methods of communication.

The information from this study will be used to help develop a functional disability demographic checklist that can be used within a point of care setting to identify adults as having a disability, to be inclusive of adults with an intellectual and developmental disability (ID/DD). Ultimately, the checklist of items developed by this study will help to improve the capture of those with ID/DD in administrative data systems used for public health surveillance and allocation of resources.

Interviewers should focus on information needed to come up with functional difficulty questions and obtain 'biographical fragments' where possible. Close contacts have another, outside perspective on the person with ID/DD's difficulties. Also, the close contact themselves may have had challenges of their own. However, the interview should focus on the person with ID/DD, and how their close contact understands challenges and barriers in their day-to-day lives.

1. Introduction and consent

- Check person can see and hear interviewer clearly
- Introduce self and NCHS
- Explain/Reiterate:
 - Purpose of research
 - Nature and length of discussion
 - Voluntary and confidential nature of research
 - Confirm privacy

- o Transcription
 - o Video and audio recording
- Start recording
 - o Verbal consent to take part
- 2. Opening discussion**
 - Describe what's fun/easy/hobby/likes/feel good
 - Current/past member of club, organization, group
 - *If needed*, description of a typical day
- 3. Difficulties / challenges in life**
 - Challenges/ problems/ dislikes /feel bad
 - Current /past difficulties or challenges in day-to-day activities? (e.g., Mobility, cognition, self-care, communication, other)
 - Level of difficulty/changes over time?
 - Barriers to overcoming difficulty/problem
 - Impact on life/daily living
 - Comparison with others
- 4. Outlook on life**
 - Determine positive / negative outlook on life
- 5. Disability / impairment**
 - Knowledge / perception of disability / how describe
 - Type of disability, if known
 - How other people describe/ view /see disability
 - Age of onset/ongoing difficulty
- 6. Household composition**
 - Living arrangements

Specific domains

- 7. Independent living**
 - Level of independence
 - Help and support with day-to-day activities (aide or caretaker / special equipment)
 - Ability to do errands alone
 - What aspects does person need help with? (Physical/mental/emotional)
 - Enough help? More help? Less help?
 - Use of aids and equipment
 - Barriers to independent living
- 8. Access to transportation (Mobility)**
 - Ability to drive
 - Barriers to transportation use
 - Ability to use public transportation
 - Cost barriers/anxiety barriers/other barriers

9. Learning

- Academic vs. non-academic learning
- Type of school attended incl. special education classes
- Qualifications obtained
- Barriers to learning
- Literacy levels
- Feelings about school/difficulties at school
- Learning as an adult
- Adapting to change

10. Form of thought

- Following a process / doing things in the right order

11. Focused attention

- Easily distracted / difficulty concentrating

12. Interaction with others

- Barriers to interacting with other people
- Social isolation / not understanding social norms
- Attitudes
 - Nervous of strangers / untrusting of strangers / fearful of other people
- Self-expression
 - Ability to express feelings/needs to others
 - Receptiveness of others to feelings/needs of person with disability

13. Economic life

- Basic transactions – paying for things in grocery store, conceptualizing amounts
- Complex transactions – managing bank account, managing finances/paying bills

14. Employment opportunities

- Employment current/past
- Barriers to employment
- Feelings about jobs
- Employment support (e.g. job coach/training)

15. Communication

- Communication style preference
- Internet access/use

16. Changes over time

- Difficulties progressing/decreasing
- Future outlook and goals

17. Ideas and suggestions

- From person being interviewed

18. Closing

- Signpost: discussion will be ending in 5 minutes
- End on a positive
- Invite participant to raise any other issues/share anything else/ ask any questions
- End interview discussion