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**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)**

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| **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.
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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
1. **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
1. **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
1. **Outlook on life**
* Determine positive / negative outlook on life
1. **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
1. **Household composition**
* Living arrangements

Specific domains

1. **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
1. **Access to transportation (Mobility)**
* Ability to drive
* Barriers to transportation use
* Ability to use public transportation
* Cost barriers/anxiety barriers/other barriers
1. **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
1. **Form of thought**
* Following a process / doing things in the right order
1. **Focused attention**
* Easily distracted / difficulty concentrating
1. **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
1. **Economic life**
* Basic transactions – paying for things in grocery store, conceptualizing amounts
* Complex transactions – managing bank account, managing finances/paying bills
1. **Employment opportunities**
* Employment current/past
* Barriers to employment
* Feelings about jobs
* Employment support (e.g. job coach/training)
1. **Communication**
* Communication style preference
* Internet access/use
1. **Ideas and suggestions**
* From person being interviewed
1. **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)**

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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.

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* Feelings about jobs
* Employment support (e.g. job coach/training)
1. **Communication**
* Communication style preference
* Internet access/use
1. **Changes over time**
* Difficulties progressing/decreasing
* Future outlook and goals
1. **Ideas and suggestions**
* From person being interviewed
1. **Closing**
* Signpost: discussion will be ending in 5 minutes
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* End interview discussion