

# Collaborating Center for Questionnaire Design and Evaluation Research

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## Findings from a Cognitive Interview Study with Adults with Intellectual Disability on the Topics of: Adult Learning, Independent Living, Disability Group Participation, and Disability Diagnosis

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### 1. INTRODUCTION

The National Center for Health Statistics' Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) conducted a qualitative evaluation study, using cognitive interviewing methods, on behalf of the Department of Health and Human Services, Administration for Community Living (ACL), Administration on Disabilities (AoD), Office of Disability Services Innovation (ODSI).

The main aim of the study was to provide an interpretive assessment of how participating respondents with intellectual disability<sup>1</sup> were able to understand and respond to questions on the topics of: adult learning, independent living, disability group participation, and disability diagnosis. These topics were selected for further investigation following a previous cognitive interview study with adults with intellectual and/or developmental disability (Wilmot & MacFadyen, 2024).<sup>2</sup>

Following Office of Management and Budget (OMB) and the Centers for Disease Control and Prevention (CDC) Human Subjects review and approval, one-on-one in-depth cognitive interviews were conducted with 10 English-speaking adult respondents with intellectual disability. Interviews were conducted remotely using video-conferencing software during January and February 2024. This report describes the findings for each of the topics under investigation, including how some of the individual questions performed and how each construct was understood.

#### Suggested citation:

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<https://wwwn.cdc.gov/qbank/report.aspx?1252>

<sup>1</sup> Intellectual disability is a condition characterized by significant limitations in both intellectual functioning and adaptive behavior that originates before the age of 22. [Criteria \(aaidd.org\)](https://www.cdc.gov/ncbddd/idd/about/what_is_id.html)

<sup>2</sup> Wilmot, A., MacFadyen, A. Findings from a Cognitive Interview Study of Survey Questions Administered with Adults with Intellectual and Development Disabilities. National Center for Health Statistics - CCQDER. Q-Bank 2024. [Wilmot 2024 NCHS IDD.pdf \(cdc.gov\)](https://wwwn.cdc.gov/qbank/report.aspx?1252)



## 2. METHODS

### 2.1. Cognitive interviewing

A one-on-one in-depth cognitive interviewing methodology was used for this study. During the interviews, questions were administered to respondents, grouped according to the topics under investigation. Qualitative cognitive and in-depth interviewing techniques were applied to help make an assessment of the phenomena captured by the questioning within the context of the respondent’s individual life experiences.

### 2.2. Study sample

A small-scale purposive sample of 10 adults, aged 18 or over, took part in this study. Recruiting respondents with intellectual disability can require a long lead-in time (Titus, 2021).<sup>3</sup> Because of the study’s small-scale nature and time constraints, researchers selected respondents classified as having intellectual disability<sup>4</sup> from those who had participated in a previous study conducted by CCQDER.<sup>5</sup> Respondents were recontacted for interview based on characteristics determined best positioned to test the questions under investigation. For example, respondents were recruited because they had different living arrangements, or they had said during the previous study that they were members of a disability support group, as well as those who had not mentioned such groups. Table 1 shows the demographic breakdown for the ten interviews.

**Table 1: Respondent demographic characteristics**

Demographics	Number of interviews (N=10)
<b>Age-group in years</b>	
18-29	2
30-49	3
50-64	3
65 or over	2
<b>Gender</b>	
Female	2
Male	8
<b>Education</b>	
Less than HS Diploma/GED	1
HS Diploma/GED	9
<b>Employment</b>	
Employed*	5
Unemployed/Economically inactive	5
<b>Race/Ethnicity</b>	
<b>Non-Hispanic</b>	10
Black or African-American	8

<sup>3</sup> Titus, A (2021). Development of “State to Local” Approach to Recruiting People With Intellectual and Developmental Disabilities for Cognitive Interviews. Presented at the 76<sup>th</sup> annual conference of the American Association of Public Opinion Research (AAPOR).

<sup>4</sup> The classification was made based on information about a respondent’s disabilities obtained during the interview directly from respondents, and verified during the discussion. Alternatively, the classification may have been made based on information obtained during a proxy interview on the respondent’s behalf. For further information on how the classification was made see: Wilmot, A., MacFadyen, A. Findings from a Cognitive Interview Study of Survey Questions Administered with Adults with Intellectual and Development Disabilities. National Center for Health Statistics - CCQDER. Q-Bank 2024. [Wilmot\\_2024\\_NCHS\\_IDD.pdf \(cdc.gov\)](#)

<sup>5</sup> The previous study took place over two rounds, conducted in 2019 and 2022. Respondents for this study were recruited from both previous rounds.

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\* When probed by the interviewer, employed respondents mostly worked part-time.

2.3 Recruitment

To provide continuity and familiarity, the same CCQDER operations staff member who had conducted the recruitment and scheduling for the previous study reached out to those selected to take part in this study. This study was carried out remotely using Zoom for Government.<sup>6</sup> The operations staff member offered and provided support to those who needed help with accessing the cognitive interview remotely, if they did not have anyone else who could help.

2.4 Data Collection

Respondents took part in a one-on-one in-depth cognitive interview lasting no more than one hour. All interviews were recorded. The study consent form was emailed to participants in advance of the interview. On the day of the interview, the operations staff member reviewed the consent form with the respondent to ensure that all aspects of the form were explained and that the respondent had the opportunity to ask any questions. Prior to the start of the interview the interviewer also reiterated the purpose of the study and the private and voluntary nature, and again gave respondents the opportunity to ask questions. The interviewer obtained verbal consent to proceed immediately prior to the interview and again, for the record, on starting the interview recording.

As part of the consenting process, both the operations staff member and the interviewer let respondents know that they did not have to answer any questions they didn’t want to answer and that they could stop the interview at any time. Then, respondents had the opportunity to practice what they will say if they find themselves in that position. For example, in one case a respondent told the operations staff member that she would say the word ‘skip’ if there was a question she preferred not to answer. She subsequently used ‘skip’ to let the operations staff member and the interviewer know that she did not want to answer questions about income (part of the demographic information collected prior to the interview) and questions about managing money (asked during the interview).

The questions used in this study are shown in Appendix 1. Interviewers used non-scripted verbal probing, consistent with an interpretivist interviewing approach (Cibelli Hibben & DeJong 2020),<sup>7</sup> to understand how and why respondents answered the questions the way they did.

Respondents received \$50 as a ‘thank you’ for participating. Because some respondents had difficulty reading or using a computer, the majority received cash, although a few chose to receive an electronic gift card alternative.

2.5 Data analysis and reporting

Analysis of cognitive interviewing data followed a systematic process of synthesis and reduction from interview to report (Miller et al., 2014).<sup>8</sup> With consent, all but one interview was video and audio recorded. One interview was audio recorded only. From the recordings, interviewers created summary notes about the way in which respondents interpreted and responded to the different questions and probes, evidenced by verbatim statements made by respondents during the interview, and observation of non-verbal behaviors.

<sup>6</sup> To comply with the CDC’s requirements to use an authorized and secure video conferencing platform through which to conduct the interviews.  
<sup>7</sup> Cibelli Hibben, K.L. & de Jong, J. (2020). Cognitive Interviewing. *Guidelines for Best Practice in Cross-Cultural Surveys*. Ann Arbor, MI: Survey Research Center, Institute for Social Research, University of Michigan. Retrieved from <https://ccsg.isr.umich.edu/chapters/pretesting/cognitive-interviewing/>  
<sup>8</sup> Miller, K., Willson, S., Chepp, V. & Ryan, J.M. (2014). Analysis. In K. Miller, S. Willson, V. Chepp & J.L. Padilla (Eds.), *Cognitive interviewing methodology*. Hoboken, NJ: Wiley.

### 3. FINDINGS

The sections below summarize findings from the 10 interviews with adults with intellectual disability, grouped by the topics: adult learning, independent living, disability group participation, and disability diagnosis. A frequency distribution table is shown indicating how respondents answered each question immediately after hearing it. However, it should be noted that these tables do not reflect any distributions that might be apparent from a quantitative probability sample.

#### 3.1 Adult learning

The following four learning questions were evaluated and probed as a set. Interviewers probed to understand what respondents considered learning, what respondents thought of as their challenges with learning, whether they thought that they needed help with learning, and whether anyone helped them with any learning difficulties they had.

When responding to the first learning question (Learn), respondents tended to consider whether they had had trouble learning more generally. Whereas the question about ‘learning new things’ (LearnNew) prompted respondents to consider learning more discrete specific tasks or skills such as using a computer. LearnNewEx (‘Do you have difficulty learning new things, for example at school, work or in other places?’), prompted some to think about school-age learning, particularly learning to read, and some to think about learning new workplace tasks, being that the question examples specify ‘school’ and ‘work.’

Nonetheless, difficulty learning to read stood apart as a significant consideration mentioned not only when asked the learning domain set of questions but also impacting responses to other domains, particularly independent living. Even respondents who did not provide a difficulty rating to the learning questions sometimes discussed reading difficulties during probing as something that was important to them. For example, one respondent, who did not provide responses to the learning questions, explained that reading had been a limitation for him when trying to progress at work or when attending adult classes. He explained, *“But when we got to the reading part, I couldn’t go past that.”* Likewise, another respondent, who said that her difficulty learning “depends” on what she is trying to learn, said, *“If reading, it’s a little bit [difficult]. I’m better at it than I used to be, but I would say that. Yeah, that is one thing.”* Difficulty reading also arose in some respondents’ considerations in the independent learning questions. For instance, when discussing the question about barriers to independent living (Limited), some respondents mentioned that they were limited in education or in life generally due to their difficulties reading. Additionally, when discussing the question about money management (MoneyMan), a respondent said that when paying bills, his mother helped him due to his difficulties reading and writing.

Some respondents, when answering the learning questions, thought about a specific learning difficulty they had, and in a few cases, they also thought about their learning disability. As one respondent said, *“I have a learning disability. And, it’s hard for me to read, write, and so I have a disability of learning.”* Other considerations of things that respondents found difficult to learn included the following: learning independent living skills, such as money management and healthy lifestyle habits, navigating social interactions, parenting, gaining computer skills, mastering work tasks, and adjusting to changes to daily and weekly routines. In other cases, though, respondents, particularly with relatively more severe cognitive difficulties, compared with other people in the sample,<sup>9</sup> were not able to provide a response to any of the learning questions. In those instances, respondents did not generalize

<sup>9</sup> Based on a non-clinical assessment by the research team after the interview was complete.

their experiences into a ‘Yes’ or ‘No’ response, noting that their difficulty “*depends*” on what sort of things they were learning. The respondents who did not provide answers to the learning set all affirmed membership in disability support groups with the membership question (Member), and some also identified as having a disability with the diagnosis question (Diagnosis) (discussed in sections 3.3 and 3.4, respectively).

Respondents tended to focus heavily on examples where they were provided, and as mentioned above, the considerations at the forefront of respondents’ minds were learning to read, learning job tasks, and for some, managing money and other independent living skills. The use of salient examples could help to reduce non-response, though they may affect respondent considerations. Therefore, asking direct questions about learning to read, learning to handle money responsibly and independently, or new job tasks may function effectively to target the learning difficulties among people with intellectual disability, as these were common experiences in the sample of respondents.

What follows is a detailed description of findings for each learning domain question.

Learn

**Do you have difficulty learning things?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don’t know

*Frequency distribution (N=10)*

Response option	Count
Yes	5
No	1
Don’t know	0
Refused	0
No response provided	4

When discussing this question, respondents tended to consider whether they had had trouble learning in a general way throughout their life. For example, respondents who thought of their current difficulties reading considered learning to read as a long-term work in progress, beginning in school and continuing to the present day. On the other hand, some thought only of school-age learning when they were younger or remembering other things they had learned in the past. A few thought about their learning disability.

All respondents were asked this first learning question, and half answered ‘Yes.’ Most respondents who answered ‘Yes’ thought of their difficulty learning to read. A few specifically considered difficulties learning to read in school, but they still faced challenges with reading as an adult. As one respondent said, “*I’m not 100% [a] reader. Some things have to be explained to me a little bit.*” Another respondent said that his difficulty reading was one of the main reasons that he needed help in his day-to-day life: “*That’s why I need help is because of my reading. That’s why I need a lot of help.*” In one case, a respondent who answered ‘Yes’ considered his primary learning difficulty to be learning money management and other independent living skills, rather than reading.

Those who did not provide a response noted that their difficulty learning varies: “*I do have difficulty learning some things...just not other things.*” Likewise, another respondent said, “*It all depends on what things. Some*

*things might be a little bit more difficult than others. I don't know what kind of things you're talking about."* Despite not being able to provide an answer, most respondents were able to speak about things they found difficult to learn when probed. For instance, one respondent spoke about the help he had learning job tasks and said, *"Yeah at the very beginning of the job we had mentors who help you learn how to do the job."* Also, a few respondents who did not provide a response still spoke about reading as something they had difficulty with. The one respondent who answered 'No' could not think of instances when she had to learn. However, during probing, she did describe occurrences when her coworkers helped her correct mistakes at work.

### LearnNew

**Sometimes people have to learn to do new things they have not done before, for example, in their job or around the house.**

**Do you have difficulty learning new things?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*Frequency distribution (N=10)*

Response option	Count
Yes	4
No	2
Don't know	0
Refused	0
No response provided	4

This question prompted respondents to think about learning more discrete specific tasks or skills, as opposed to the prior question, 'Learn.' Those who answered 'Yes' to this question considered learning things such as new tasks at their job, a new transportation route, computer skills, and healthy lifestyle habits. Two of the respondents who answered 'Yes' also mentioned enjoying learning new things. As one respondent said, *"Yes, because I want to try it. I want to try learning new things I don't know yet."*

Four people did not provide an answer to 'LearnNew.' In all but one case these people had also not provided a level of difficulty response selection for 'Learn.' Generally, the same reasoning was given - that whether they have difficulty *"depends"* on what they are learning. The one respondent who had answered 'Yes' to 'Learn' but did not provide a response to 'LearnNew' reiterated his need for his girlfriend's help when it came to reading. He said, *"I do a lot of things for myself around that house. But when it comes to reading, then she has to help."* Another respondent who did not provide a response to 'LearnNew' said that his abilities had changed over time, explaining that he had more difficulty when he was younger, and now he has more help from his supervisor.

### Effect of the introduction

A few respondents, who were interviewed early on, were focused on the examples in the introduction. For instance, one respondent, who answered 'No,' said that the introduction made him think about tasks 'around the house,' such as cooking and cleaning. Since he was unemployed, the job example in the introduction applied less to him. He explained, *"Well I know how to cook and clean – that's no problem. I can cook because my mom taught me."* Likewise, another respondent focused on the introduction wording, and ultimately was not able to

provide a response. He said that he was able to learn “*some things*” without difficulty, but others took him more time. He said,

*“When I’m home, I’m good with cleaning and everything. I like to walk. Some things like tasks – putting things together, it takes [time] on that. I end up getting it, but it could take me a while to get it.”*

Due to the effect of the introduction on respondents taking part in these early interviews, the interviewers decided to probe on the concepts in the introduction without reading it, for the remaining interviews. Without the introduction respondents considered learning any new things, not just new things in their job or around the house. For example, one respondent, who had not provided a response to ‘Learn,’ explained why he answered ‘Yes’ to ‘LearnNew’ in the following way:

*“I think I have difficulty learning some new things – not a lot of new things. For instance, it’s going to be hard. I’m going to Florida to visit my grandma in a week, and it’s going to be hard to learn a new area of the airport. So, I guess the answer would be ‘yes.’”*

### LearnNewEx

**Do you have difficulty learning new things, for example at school, work or in other places?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don’t know

### *Frequency distribution (N=10)*

Response option	Count
Yes	5
No	1
Don’t know	0
Refused	0
No response provided	4

Respondents tended to answer based on whether they felt they had difficulties in school, including learning to read, or learning tasks at work, whichever was most relevant to them, focusing on the examples in the question: ‘school’ and ‘work.’ In some cases, respondents thought about learning in school when they were younger, and a few considered learning in adult education classes or in adult recreational classes, such as art or dance class. For instance, one respondent, who answered ‘Yes,’ explained that he did not have difficulty at work, “*...they loved me because all I like to do was work,*” but when he was in school, he had a very hard time sitting still and focusing. He said, “*I had what they call the ‘ADHD’ and now I’m watching my grandkids with it.*” A few respondents, when discussing the help they received learning in school, said that they had help from Special Education classes to learn reading, writing, or math. The one respondent who answered ‘No’ was thinking about her adult recreational classes, when answering. She explained, “*I enjoy art class.*”

One respondent, who answered ‘Yes,’ understood the question as asking him to choose whether he had difficulty learning in school, work, or other places. Rather than a ‘Yes’ or ‘No’ answer, he said, “*I’d say work and other places*” in response. In his case, he thought about difficulties he sometimes had learning new skills at work and learning new sports skills for his Special Olympics team.

Four respondents who were asked this question did not provide a response. In those cases, one person repeated his explanation for the prior learning question (LearnNew), to which he had answered ‘Yes.’ He said, *“I’m always willing to learn something new.”* Another respondent, however, thought about the lack of formal adult education classes in his city. While he had tried to participate in an adult reading class, he was told he could no longer attend due to his slower learning pace.

### LearnDiff

**How much difficulty do you have [learning / learning new] things? Would you say... no difficulty, some difficulty, a lot of difficulty or cannot do at all?**

- 1 No difficulty
- 2 Some difficulty
- 3 A lot of difficulty
- 4 Cannot do at all
- 7 Refused
- 9 Don’t know

### *Frequency distribution (N=10)*

Response option	Count
No difficulty	0
Some difficulty	4
A lot of difficulty	2
Cannot do at all	0
Don’t know	0
Refused	0
No response provided	1
Not asked by interviewer	3

When respondents had indicated that they had difficulty learning things or learning new things, interviewers probed on how much difficulty they had. Respondents answered the same way, to both prompts. Two respondents selected ‘a lot of difficulty’ focusing on their reading difficulties. As one respondent noted, *“...when I pick up a book I always have to stop, you understand? I’m not always putting it together...You get to the spot where you want to stop being agitated that you can’t read.”* The remainder who were asked this question answered ‘some difficulty.’ These respondents said that they were making improvements over time with their difficulties, that they only needed ‘some help’ with their difficulties, such as learning new skills at work or new transportation routes. For example, one respondent said, *“...because the jobs I have I have to take transportation ...and, it’s difficult to find that and know how to do it to the best of my ability, I guess you could say.”* When thinking about learning new things, one respondent, who had answered ‘some difficulty,’ said that he found it difficult to adjust his schedule to interruptions and change. *“I guess I could also say what’s hard is I volunteer – I go into work and then I come home, and then I have to get ready to volunteer the next day. So, it’s been an adjustment – getting the sleeping patterns.”*

## 3.2 Independent living

### AideAssist

**Do you have an aide or personal assistant who helps you with everyday tasks (for example, shopping or cooking)?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*Frequency distribution (N=10)*

Response option	Count
Yes	2
No	6
Don't know	0
Refused	0
No response provided	2

#### FamAssist

**Does a family member help you with everyday tasks (for example, shopping or cooking)?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*Frequency distribution (N=10)*

Response option	Count
Yes	3
No	4
Don't know	0
Refused	0
No response provided	0
Not asked by interviewer	2

#### DayAssist

**Do you have someone to assist you with your day-to-day activities at home or outside?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*Frequency distribution (N=10)*

Response option	Count
Yes	5
No	3
Don't know	0
Refused	0
No response provided	1
Not asked by interviewer	1

The set of three questions shown above were intended to help establish whether the respondent received any assistance with everyday tasks carried out inside or outside of the home. Additionally, respondents were probed on

whether they thought that they needed assistance, the type of assistance received, the amount and frequency of the assistance received. At the discretion of the interviewer, sometimes the questions were initially administered without the use of the examples shown (i.e. shopping or cooking) in order to establish, without priming, the types of tasks respondents considered when answering.

During probing, interviewers established that all respondents received some help or assistance from other people. Help was provided by a relative (including blood relative or partner), and/or from an aide, or from a team of support people. Older respondents, aged 50 or over, did not receive help from a relative. They reported receiving help from an aide or support team, explaining that they had learned to become more independent over time.

Most respondents appeared to understand these three questions as intended and most appeared to answer correctly - verified during discussion with the interviewer. Respondents demonstrated an understanding that the first question in this sequence (AideAssist) was asking about a more formal arrangement with someone they had not known previously, whereas the second question in the sequence (FamAssist) was asking about a more informal arrangement whereby help was provided by a family member. The third question in this series (DayAssist) was generally able to capture whether anyone provided help, to include help from friends or neighbors, in addition to, or instead of, a personal aide or family member.

Those who lived alone described the tasks that their aide helped them with, while those who described help from family members either lived with those family members or lived close by, but not alone. One respondent, who lived with his spouse who also had a disability, answered ‘No’ to all of these questions. This was because he did not have an aide or family member who helped with everyday tasks but instead described a team of people supporting him to live independently and on whom he could call, if needed. This team included a person he referred to as a ‘provider,’ a nutritionist, and a social worker.

When answering these questions respondents considered the kind of help that they received, describing help with bathing, cooking, cleaning, grocery shopping, budgeting, transportation to medical appointments, and completing paperwork at medical appointments. In addition to these tasks, those describing help from a family member also mentioned help with scheduling appointments and leisure events, help with transportation to leisure events, as well as help with paying bills - which one respondent explained was a task *“for family only”* and not something she would ask her aide to do. As apparent in previous cognitive testing with people with intellectual disability, some respondents had a positive, can-do outlook on life, and a desire to demonstrate their independence. As a result, one respondent discounted help with what he perceived to be more minor tasks: *“No I do not. I do my own tasks on my own, other than the cooking part. I have someone who helps me with cooking. I don’t have someone who helps me with bathing or something like that.”* Another respondent, living in a small-group home, did not consider the daily services provided by staff, such as cooking and cleaning, as him receiving help or assistance, although he answered ‘Yes’ to the question about help from a family member because his mother drove him to his job and to his leisure activities: *“She’ll take me to go work, to bowling.”*

As mentioned in the introduction to this section sometimes interviewers administered the question without examples. Without the use of the examples a young respondent in her 20s, who had always lived at home with family members, did not consider help with everyday tasks that she was used to receiving, such as meal preparation. This respondent answered ‘No’ to all three questions but during discussion with the interviewer described how her mother prepared her main meals and helped her with cooking pancakes for breakfast.

Respondents demonstrated an understanding of the terms ‘aide’ and ‘personal assistant’ during probing. Some respondents used the term ‘aide’ (but not ‘personal assistant’) spontaneously during the interview, to describe the

person who helped them with daily activities. Respondents described help provided by their aide at set times, on a regular basis: *“I have an aide 7 days a week 8 hours a day.”* Two respondents used the term ‘provider’ instead, but in different contexts. One described his provider as providing similar support to that of an aide on two days every week – helping with grocery shopping, budgeting, and taking him to hospital appointments. However, the other was clear on the difference between the services provided by an aide and those from his provider. He explained that a relative had an aide who provided hands-on assistance every day for a set number of hours, *“...he makes sure he is taking his medications and things like that,”* whereas, the respondent only had contact with his provider once every couple of weeks and the role of his provider was to ensure that he had what he needed to remain living independently: *“...he oversees our needs and that they are being met.”* His provider was part of a team of people who provided support for independent living. Both of these respondents did not provide a response to the question ‘AideAssist.’

One respondent hesitated and answered *“Not really”* after hearing the first question in this sequence about help from an aide or personal assistant, considering if his sister fulfilled that role. The interviewer asked the question again after the question about help from a family member and the response was an emphatic *“No,”* suggesting that the order in which these questions are asked could be switched or the questioning combined.

In regard to the question ‘DayAssist’, the use of the phrase ‘day-to-day activities,’ in combination with the term ‘outside’ [of the home] led a few respondents to consider leisure activities and social events that they took part in. One respondent, who answered ‘No’ to this question, thought that the question was asking him about scheduling his day-to-day activities:

*“I can do my own day-to-day activities. I can put it on my schedule, what I’m going to do. Because I have a calendar. And I just put activities, whatever I’m going to do. Like if I go to say a family dinner maybe or if I have a doctor’s appointment, I scheduled it. Or possibly if I want to go to the movies with friends maybe.”*

Additionally, the use of the term ‘assist’ rather than ‘help’ appeared to have a different meaning for one respondent who, after asking for the question to be repeated, said, *“Not assist me, but sometimes help.”*

The examples used in the questions were important to a few respondents who indicated that they were unsure as to the meaning of the term ‘everyday task’ without them. One respondent asked for examples when asked the question ‘DayAssist’: *“Yes, but it all depends on what the activity is.”*

Again, respondents were keen to show that they could live independently and did not need help all of the time, but they could call on people for help if needed. Respondents talked about being able to ask their formal support network for help, including organizations that they were members of, when they needed it, as well as their informal network of family members: *“She [sister] helps me if I need it, but if I don’t need it, she don’t help me.”* Sometimes there was a family member who provided the bulk of the help and support, but other family members who helped on a less frequent basis. A few respondents also mentioned that they could ask neighbors or people at work for help if they needed to. Even when respondents had an aide, interviewers were told that it was the respondent who made the decisions. For example, one respondent said that he decides when he needs to go to the grocery store and what to buy – his aide was there to help him only because he is a wheelchair user.

Bearing in mind that some respondents with intellectual disability can be quite literal in their interpretation of question wording, and rely on more concrete rather than abstract concepts in order to make a more accurate interpretation of the questioning. Avoiding terms such as ‘everyday tasks’ and ‘day-to-day activities,’ and using example in the question stem may help to make the questioning clearer to respondents with intellectual disability.

Based on the findings from this study, asking more general questions about whether someone provides help, alongside the use of specific examples such as grocery shopping, paying bills, scheduling or transportation may likely suffice.

### MoneyMan

**Does someone help you manage your money, such as pay your bills or help you with banking?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*Frequency distribution (N=10)*

Response option	Count
Yes	6
No	1
Don't know	0
Refused	1
No response provided	2

Most respondents answered 'Yes' to this question. Focusing on the examples provided in the question stem respondents explained how family members helped them with paying bills and 'online' banking. In some cases, this was because of respondent difficulties with reading and writing: *"My mom will help me with writing out my checks and bills."* In discussion with the interviewer a few respondents spontaneously mentioned the importance of budgeting and on saving money: *"I definitely need to work on saving money. Because I have a habit of spending it on crazy things. Not big expensive, but just cheap things."* One respondent answered 'No' to this question explaining that someone had helped him to set up 'autopay' and his bills were now paid automatically. Two respondents did not provide a response. One of these respondents explained that a team of people provided oversight to ensure that he was managing his money well, and they would intervene if he was not. He said that there was no one person he would go to for help with managing his money. Instead, his social worker and provider would meet with him and his spouse to discuss any difficulties they might be having: *"If I needed help I would ask for it but I've lived that life. I want to be independent."* The other respondent said that in the past he had someone who helped him with money management but that no one currently helped him to pay bills or with banking. One respondent declined to answer the question because it was about money.

The examples provided did not help establish whether respondents had difficulty handling money, such as comprehension of how much things cost or whether they had received the correct change. The use of different examples, to include handling money, may improve validity. On the other hand, as the question stands, it may simply be providing another measure of a respondent's ability to read or write.

### OwnDec

**Do you 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?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*Frequency distribution (N=10)*

Response option	Count
Yes	9
No	0
Don't know	0
Refused	0
No response provided	1

Respondents focused on the examples used in the question stem when answering this question. All but one respondent answered 'Yes.' One respondent did not provide an answer.

It was evident from the discussions that it was very important to respondents that they were able to make decisions for themselves. In fact, one respondent told the interviewer that the most important thing to him in life was that people did not make decisions for him or speak for him. Perhaps as a result, respondents focused on an example used in the question stem that they could answer affirmatively. All but one answered 'Yes' about making decisions on what to eat. Respondents living with family explained that they would have a say about what food was purchased at the grocery store and therefore what they ate. Those who had aides to help with shopping and cooking explained that it was the respondent making the decisions about what food to purchase and therefore what they ate, even if their aide provided assistance. Some respondents said that they also had complete control over what they did in their spare time, describing sports and leisure activities that they took part in. The respondent living in a small-group home setting, where meals were provided, answered 'Yes' to this question based on the fact that he made his own decisions about how to spend his free time. A respondent, who lived with his mother, answered 'Yes' based on making his own decisions about what to eat and how he spent his leisure time, although he also said that his mother helped him with scheduling that time:

*"Well because my mom worries about me a lot, I'll ask her about the activity I have planned. If she says yes, then I can do it. If she says no, then maybe I can do it another time or just don't do it at all. It's for my safety, you know?"*

Another respondent also mentioned that he consulted with his parents on how best to spend his free time:

*"I do with the eating. But I know that free time is hard for me. I get my mom, for example, my mom helping me will write down, 'this is what you can do with your free time. You can go hang out with a friend, you can go to the library, you can do this and that.'"*

Although respondents described having input in where they lived, some described their limited choices based on what they could afford or what the authorities would provide. A few described help with finding suitable accommodation: *"My mom found the apartment for me. To live over there....so that's how I got to being over there. But, it's because I wanted something closer to the job."* The one respondent who did not provide an answer to this question explained that although he decided what to eat and how to spend his free time, he was still dependent on the authorities for his accommodation: *"What to eat I make my own decision for. Where to live – they still help me with that."* One respondent interpreted this aspect of the question more literally as asking if he was currently deciding on where he should live. He said that he loved where he was currently living so he wasn't currently deciding where to live, but he could one day.

## Limited

**There are many reasons why people can't take part in activities as much as they would like to. This could be because of health, cost or lack of services for example. Are you limited in the following areas of life for any reason...**

*Individual Prompt – Code all that apply [Yes/No]*

- (1) Education?
- (2) Work?
- (3) Transportation?
- (4) Personal relationships?
- (5) Leisure?
- (6) None of these

*Frequency distribution (N=10)*

Response option*	Count
Education	2
Work	1
Transportation	1
Personal relationships	2
Leisure	1
None of these	1
Don't know	0
Refused	0
No response provided	2
Not asked by interviewer	2

*\*Multiple response items could be selected for this question*

This question was lengthy in comparison to others in this question set, and several respondents either requested that it be repeated or discussed their answers piecemeal. Interviewers adapted the administration of the question as needed, adjusting to a more conversational style or probing based on respondent needs item by item. Some respondents answered 'Sometimes' to certain items rather than answering 'Yes' or 'No.'

When considering this question, many respondents thought about whether they felt restricted, were "*struggling with anything*," or wanted to work on improving any of the response prompt items. As one respondent said, he felt the question was asking "*If, like, if a disability [is] hold[ing] me back.*" Another person, who selected 'work' explained, "*I feel like I'm a little limited in work because only because I don't work all the time [...] If I had my choice I would want to work more often.*" In a few cases, however, respondents considered whether they had any access at all to the prompt items, which was associated with non-response and potential confusion. For instance, one respondent said, "*I don't know*" when he was asked about 'education,' and when asked about 'Work' he said, "*Work? Yeah, I work.*"

Respondents who discussed their 'Education' were thinking about their limitations in reading, and the fact that they had not learned to read well while in school. However, not all respondents with reading difficulties selected 'Education.'

One respondent selected ‘Work,’ and, as described above, he felt he could work more than he already was working. However, another respondent who said that he had been looking for work for a long time, applying to hundreds of jobs, did not select ‘Work.’ He focused on his successes in life and selected ‘None of these,’ and he said, *“I’ve done so well in my life. I have struggled in finding employment though.”*

Respondents who discussed ‘Transportation’ thought about how their public transit could be improved or how decreases in transit funding and access were deeply concerning to them. For instance, one respondent, who had not initially selected ‘Transportation,’ changed his mind during probing. He said, *“No my transportation is a problem because I get on the bus every day. I transport my grandkids on the bus to school and I pick them up from school [...] it is a limitation. It’s working out well, but it’s still not good. I want the bus to come right to the door.”* However, not all respondents who had to rely on others for rides or had long commutes on transit said that transportation was a limitation. One person, who did not provide a response, said he relied on his mother to take him places: *“I don’t have a problem; I understand that she has things to do. It does make me upset sometimes. But I have to remember, that it is my ride back and forth. I’m kind of just fine with it.”*

Respondents who discussed ‘Personal relationships’ thought about their interactions with family and friends. For example, one person said that he had a difficult time expressing his opinions when he was out with friends. Another respondent said, ‘Sometimes,’ rather than ‘Yes’ or ‘No,’ and was thinking about his relationship with his girlfriend. He explained, *“Because sometimes you have problems in your relationship, and you have to be able to cope with each other when both of you have a disability [...] we learn how to advocate for other people and ourselves.”*

Regarding ‘Leisure’ and limitations in leisure, respondents all reported that they were current members of disability support groups and described active social lives. A few respondents said that they did not know what the word ‘Leisure’ meant. In those cases, interviewers probed respondents about their ‘free time’ or ‘things they do for fun.’ The one respondent who selected ‘Leisure’ said that he used to play tennis, but he could not play any longer since he used a wheelchair. One aspect of leisure that was not captured by the question, was a respondent’s difficulty deciding what to do with his free time. He had only selected ‘Work’ and explained, *“I just know I think, ‘what do I do with my activities when I’m not working?’ Sometimes I call my mom and say, ‘what should I do?’”*

This question inconsistently captured barriers to independent living among the respondents in this study. Also, respondents at times answered based on whether they felt limited, some did not indicate having any limitations, despite feeling dissatisfied or restricted. Respondents with intellectual disability may answer more consistently to direct questions without compound components.

### 3.3 Disability group participation

#### Member

**[Are you/Have you ever been] a member of a group which supports people with (intellectual) disabilities, (like the Arc or Special Olympics)?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don’t know

*Frequency distribution (N=10)*

Response option	Count
Yes	8
No	2
Don't know	0
Refused	0

All respondents were asked this question. However, for those who had not indicated prior during the interview that they were aware of having intellectual disability, the question was read as follows: ‘Are you a member of a group which supports people with disabilities?’ This question was located towards the end of the question set, and all respondents had at that point indicated that they had a disability, at least in a general sense, before responding.

All but two respondents answered ‘Yes’ to this question. The respondents who answered ‘Yes’ were all members of Special Olympics, though not all were not recruited as such, and, in many cases, several other groups as well. Indeed, as part of the purposive sampling for this study, the research team aimed to interview people who were and were not members of groups who support people with disabilities. However, group membership was more widespread than the team initially thought. As one respondent said, *“Yes, both...and many others.”* Likewise, another respondent noted, *“I always keep myself busy doing something.”* Respondents spoke positively about their experiences in disability support groups, saying that they helped respondents realize their potential, helped them with skills, and helped them socialize. One respondent even said that the group he participated in helped parents with disabilities regain custody over their children: *“We Zoom every month – twice a month. We all meet up - people with disabilities, people who got their kids taken – we help them get their kids back. A lot of stuff. People who don't know their rights with a disability.”*

The two respondents who answered ‘No’ actually were part of groups that support people with intellectual disability, and they had answered ‘No’ in error. That was because they were not part of Special Olympics or ARC at the time of the interviews, and they had focused on the examples in the question when answering. The use of the examples, Special Olympics and ARC, though widely known and with large memberships, were associated with response error. When the examples were not used, respondents still understood the intent of the question.

### 3.4 Disability Diagnosis

#### Diagnosis

**Have you ever been told that you have an intellectual or developmental disability?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*Frequency distribution (N=10)*

Response option	Count
Yes	7
No	2
Don't know	0
Refused	0
Not asked by interviewer	1

Although respondents were selected for interview on the basis that they had been classified in a previous study as having intellectual disability,<sup>10</sup> this question was asked only of people who had provided sufficient indication during their interview for this study that they had intellectual disability, even if they had not used that specific terminology. This question was administered by the interviewer during nine of the 10 interviews conducted.

Some respondents used the term ‘intellectual disability’ spontaneously during the interview. Nevertheless, some used or said that they preferred the term ‘learning disability,’ or they described their disability in terms of a coexisting condition or preferred not to use labels to describe their disability. For the purposes of this evaluation the question tested was deliberately left broad. Specific mention of the medical profession is required to achieve a measure of medical diagnosis.

Two respondents answered ‘No’ to this question. One interpreted it as asking whether other people around him knew of his intellectual disability. He excluded the medical profession when making his ‘No’ response, explaining,

*“Well the doctors have, the doctors already know. I really, I don’t really say that because people don’t know that I’m special needs. A lot of people don’t know that. They just look at me like I’m a normal guy. So they don’t really know that.”*

The other said, *“I don’t believe so, no.”* This respondent had indicated that he knew that he had a disability, describing being a member of Special Olympics and attending special education classes in the past, but had not used the terms ‘intellectual’ or ‘developmental’ disability thus far during the interview. It is possible that he did not relate to the terminology used in the question stem.

Seven respondents answered ‘Yes’ to this question. Although some had used the term ‘intellectual disability’ during the interview, some said that they did not use that term themselves and preferred the term ‘learning disability.’ *“Well I’d probably say ‘Yes’ but I have a learning disability.”* A couple of respondents in the oldest age group, who answered ‘Yes’ to this question, hesitated on hearing it and recounted how they had been referred to as *“retarded”* during their youth. One said that although he had been told that he has intellectual disability, it was written in his medical notes, but he would use the term ‘learning disability.’ However, he went on to say that he preferred not to label his disability at all, explaining that over time the nomenclature changes: *“We don’t use the R word no more. It would be under the R word and we don’t use that anymore.”* This respondent said that the use of a label distracts from what the person with the disability can achieve: *“...with Special Olympics it gave me that confidence. We don’t look at any labels. We look at the ability of the person.”* Another respondent, who answered ‘Yes’ to this question, referred to having Cerebral Palsy, rather than intellectual disability. In response to this question she said, *“I do have a disability, I have Cerebral Palsy.”*

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<sup>10</sup> Wilmot, A., MacFadyen, A. Findings from a Cognitive Interview Study of Survey Questions Administered with Adults with Intellectual and Development Disabilities. National Center for Health Statistics. Q-Bank 2024. [Wilmot\\_2024\\_NCHS\\_IDD.pdf\(cdc.gov\)](https://www.cdc.gov/nchs/idd/pdf/cdc.gov)

## APPENDIX 1:

### Questions forming the evaluation

#### Adult Learning

##### **Do you have difficulty learning things?**

Does anyone help you learn things? Do you need help learning things?

(Sometimes people have to learn to do new things they have not done before, for example, in their job or around the house.)

##### **Do you have difficulty learning new things?**

Does anyone help you learn new things? Do you need help to learn new things?

##### **Do you have difficulty learning new things, for example at school, work or in other places?**

*If has difficulty learning [new things] then:*

##### **How much difficulty do you have [learning / learning new things]? Would you say...**

no difficulty, some difficulty, a lot of difficulty or cannot do at all?

How much help do you need [learning/learning new things]? Would you say...no help, some help, a lot of help, or cannot do at all?

#### Independent living

**Do you [have/need] an aide or personal assistant who helps you with everyday tasks** (for example, shopping or cooking)?

**[Does a family member help you / Do you need help from a family member] with everyday tasks** (for example, shopping or cooking)?

**Do you [have/need] someone to assist you with your day-to-day activities at home or outside?**

**[Does someone /do you need someone to] help you manage your money, such as pay your bills or help you with banking?**

**Do you 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?**

**There are many reasons why people can't take part in activities as much as they would like to. This could be because of health, cost or lack of services for example. Are you limited in the following areas of life for any reason...**

*Individual Prompt – Code all that apply*

- (1) Education?
- (2) Work?
- (3) Transportation?
- (4) Personal relationships?
- (5) Leisure?
- (6) None of these

### **Disability group participation**

*(Asked if the respondent indicated that they are aware that they have a disability.)*

**[Are you/Have you ever been] a member of a group which supports people with (intellectual) disabilities,**  
(like the Arc or Special Olympics)?

### **Diagnosis**

*(Asked if respondent indicated that they were aware that they had a disability.)*

**Have you ever been told that you have an intellectual or developmental disability?**

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